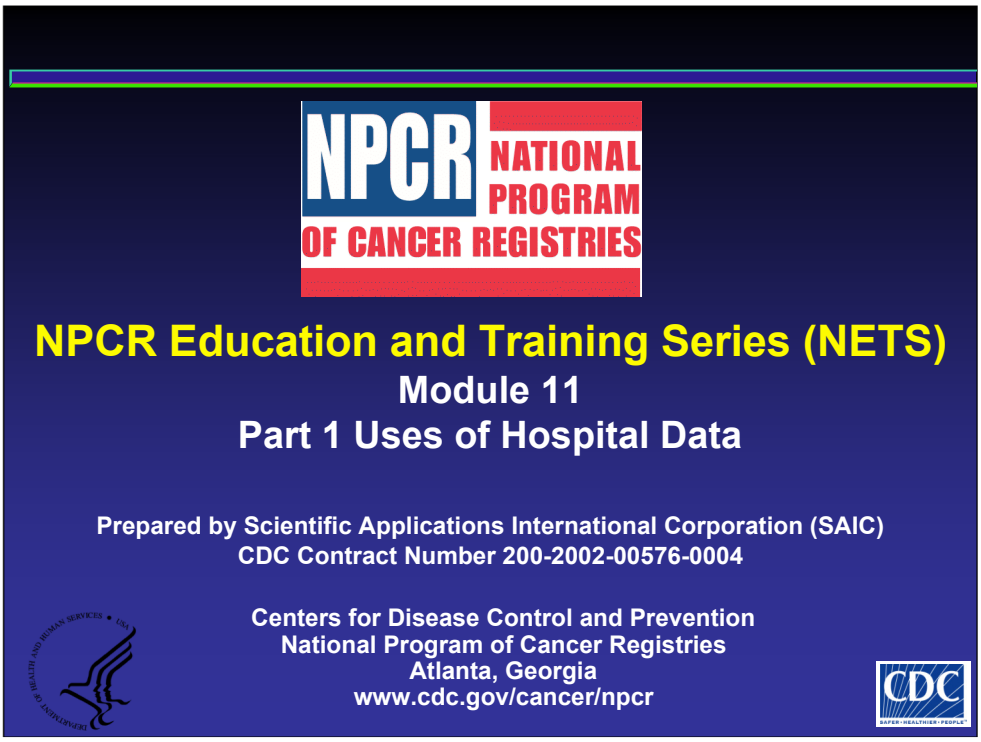
NPCR
NATIONAL
PROGRAM
OF CANCER REGISTRIES
NPCR Education and Training Series (NETS)
Module 11
Part 1 Uses of Hospital Data
Prepared by Scientific Applications International Corporation (SAIC)
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Centers for Disease Control and Prevention
National Program of Cancer Registries
Atlanta, Georgia
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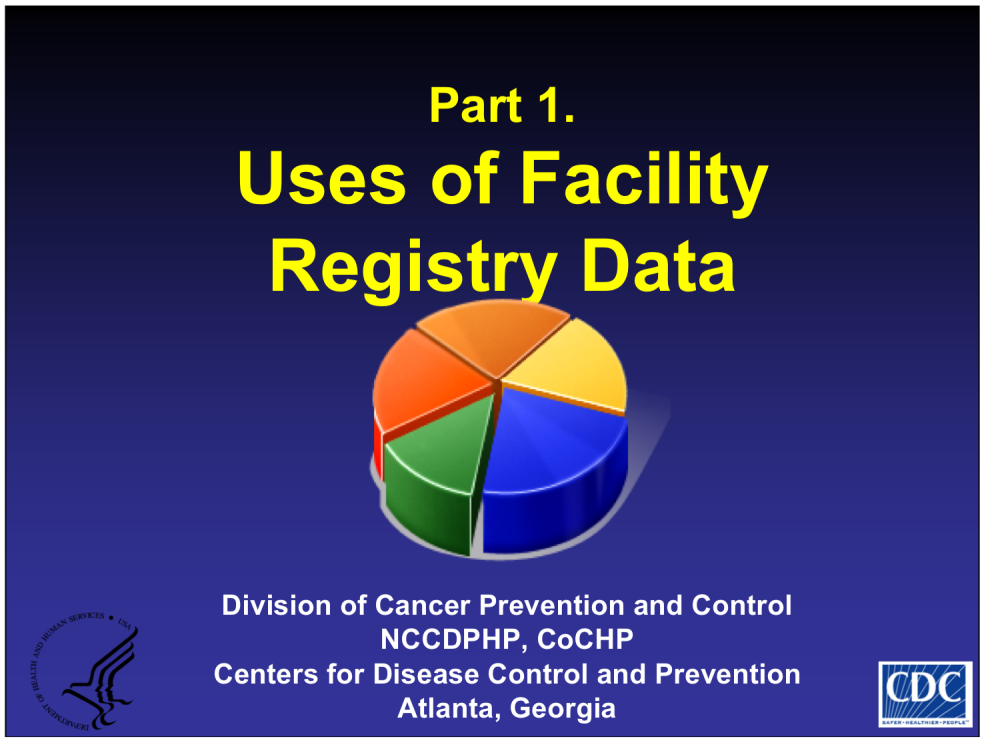
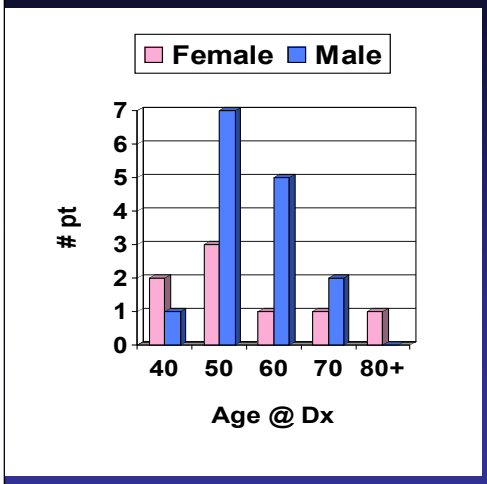
CDC



This presentation provides information on how to present data and the value of cancer registry data through its many uses.

(graphic Microsoft clipart)

Age at Diagnosis, Kidney Cancer



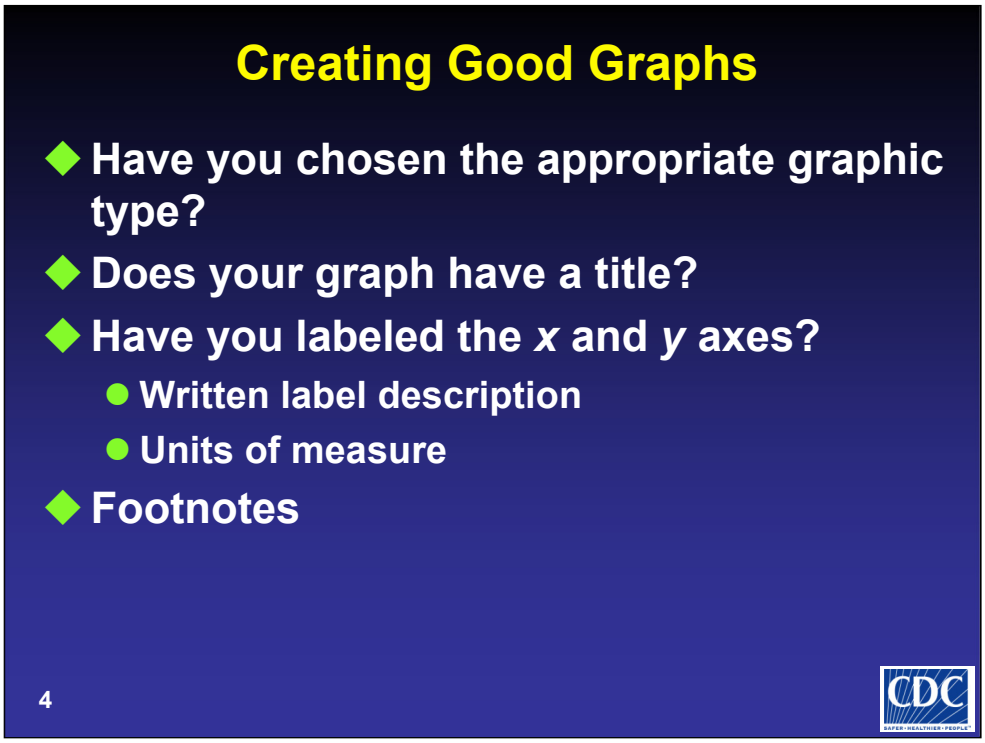
Age	M	%	F	%
40-49	1	6.7	2	25
50-59	7	46.7	3	37.5
60-69	5	33.3	1	12.5
70-79	2	13.3	1	12.5
80-89	0	0	1	12.5
TOTAL	15	100	8	100

3

First, let's look at how we present our data.

This is the same data expressed in two different ways: a graph and a table. But which one is easier or faster to understand? Which one should you hand to a busy doctor?

One thing to pay attention to when running tables in your software is how percentages are calculated. For example, on the table, are the percentages of male and female calculated by comparing males to total number of males, or males to total number of cases? If you can't explain the columns of percentages, you may want to consider removing them from the graphs.

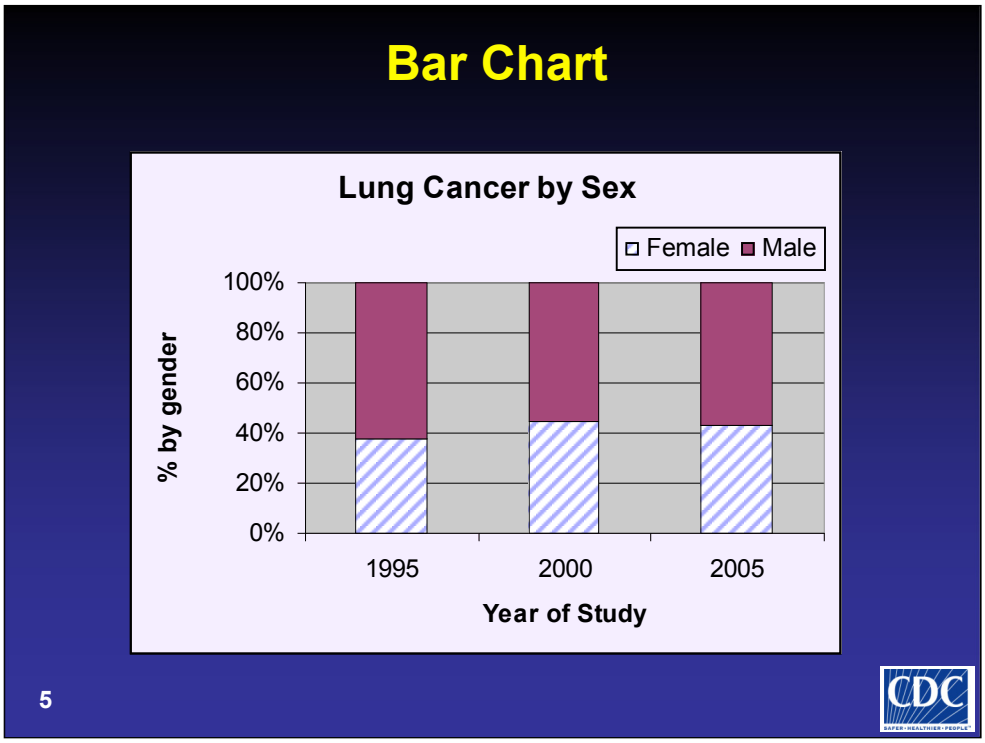


Here are some general thoughts about how to display data. Whenever possible, a graph is the most concise presentation we can give. A graph shows the relationship between changing variables. According to www.sciencebuddies.org, the first three main bullets are some good questions for us to ask ourselves about our graphs. We will look at some types in the next few slides.

A graph title should answer, “why is this graph being shown”?

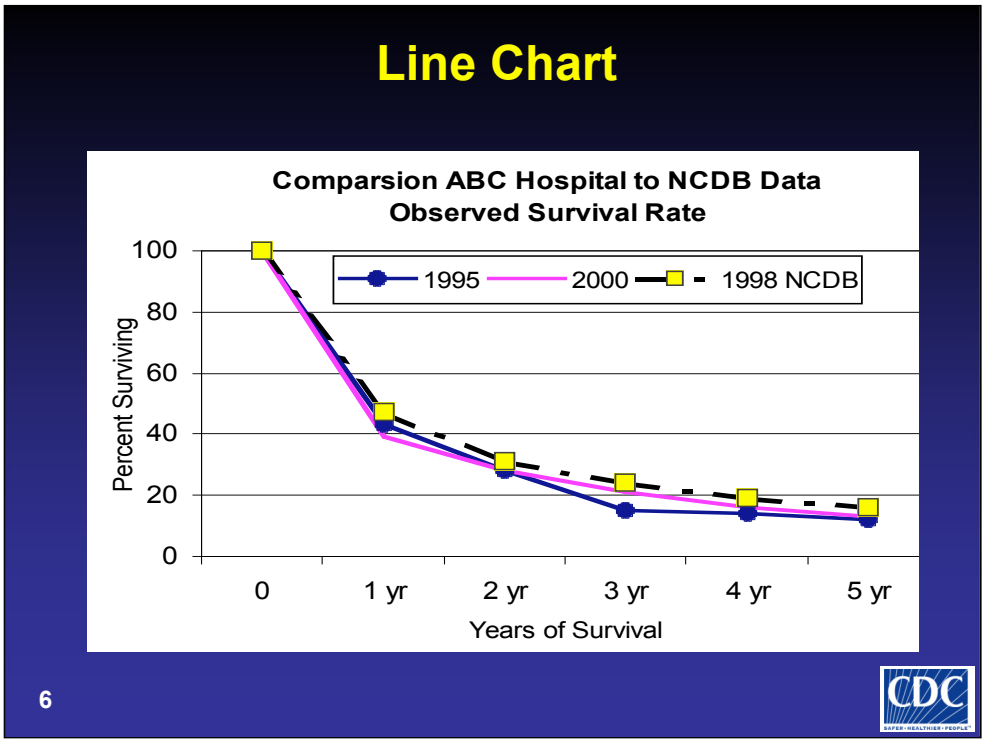
The axis labels describe what was being measured, and the units of measure tell how it was measured.

Footnotes could explain missing data (for example, cases with unknown stage were not included). You should always include “Data from XYZ Cancer Registry” as a credit line anytime you produce a graph.



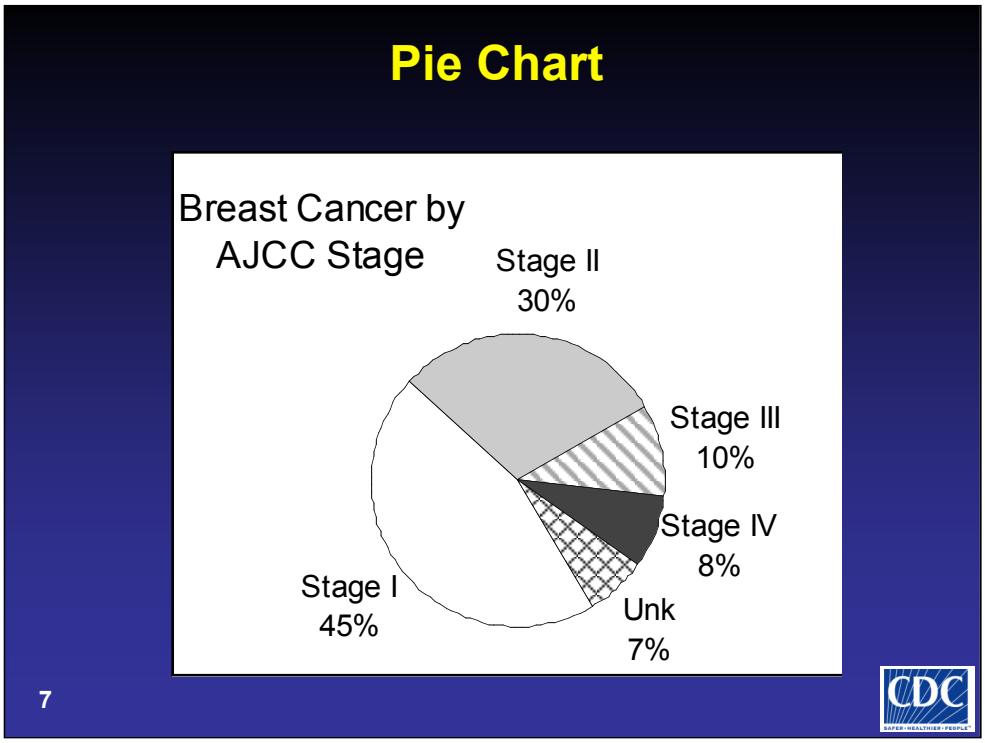
A bar chart is useful for comparing two or more sets of data. Bar charts can have vertical (known as column bars in Excel) or horizontal bars, depending on how many bars we need, and what we're trying to illustrate. This graph used stacked bars. It is showing us the percentage of each group by year, and the bars together add up to 100% of the patients in each year. Rather than showing six individual groups (Male in 1995, Female in 1995, etc.), this showed us the same information but is less cluttered.

Note the background to the graph was left gray as it was created in Excel. Does that make it harder or easier to read?



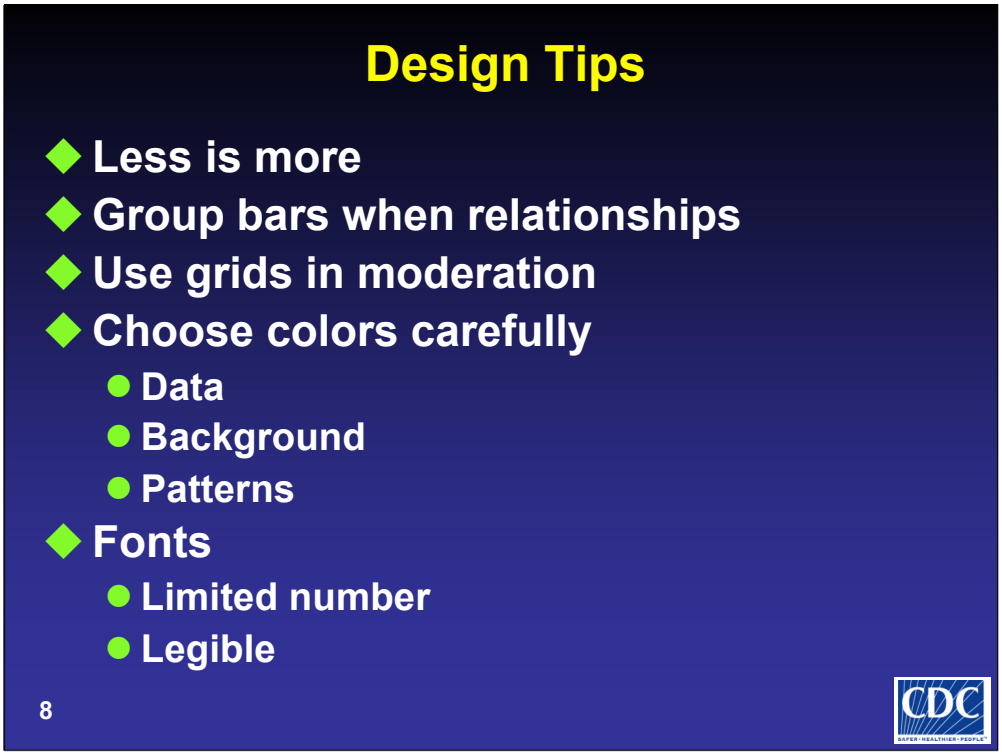
We frequently use line charts when comparing two or more variables over time. Lines show us patterns or changes. The legend for this graph was moved so that it could be placed in the unused white space in the graph, thereby allowing the graph itself to be made larger. Excel has standard colors that are the default, but you, as the designer, can choose the colors, what symbols go on the lines, and even whether the lines should be solid, dashed, or dotted. With a white background, the colors can stand out more. Had the lines been more separated, we could have made the intensity of the lines thicker.

Look at this graph. Do you know what this graph is comparing? The title isn't very clear. Is it all cancers in the registry? Or a certain site? Is it all stages? It may have seemed clear to the registrar who produced it, but this is why we recommend having someone else read your material; to look for little details that may have been missed.



Pie charts show the contribution of each part to the whole. A pie is 360 degrees, so each percentage point is 3.6 degrees.

This graph is in black and white because not all of us have color printers available. We can still vary our data by using shades of gray and/or patterns within the graph. Rather than having the legend that tells us what each color or pattern illustrates, this graph shows the labels beside the section of the pie, as well as the percentage of area within that section that the data represents. We could have chosen to show the exact number of cases instead. With Excel, you do not need to calculate the percentages. Just type in the actual numbers for each group and Excel will do the calculation of how much each pie section should contain.



Here are a few design tips to keep in mind when you are creating graphics to display your data, whether it is hospital data for a cancer committee meeting or central registry data for a report to the legislature.

•Less is more. Do not try to include too much data in one graph. If you find your graph is too crowded with bars or the pie sections are too small, perhaps you should create more than one graph, or use a table.

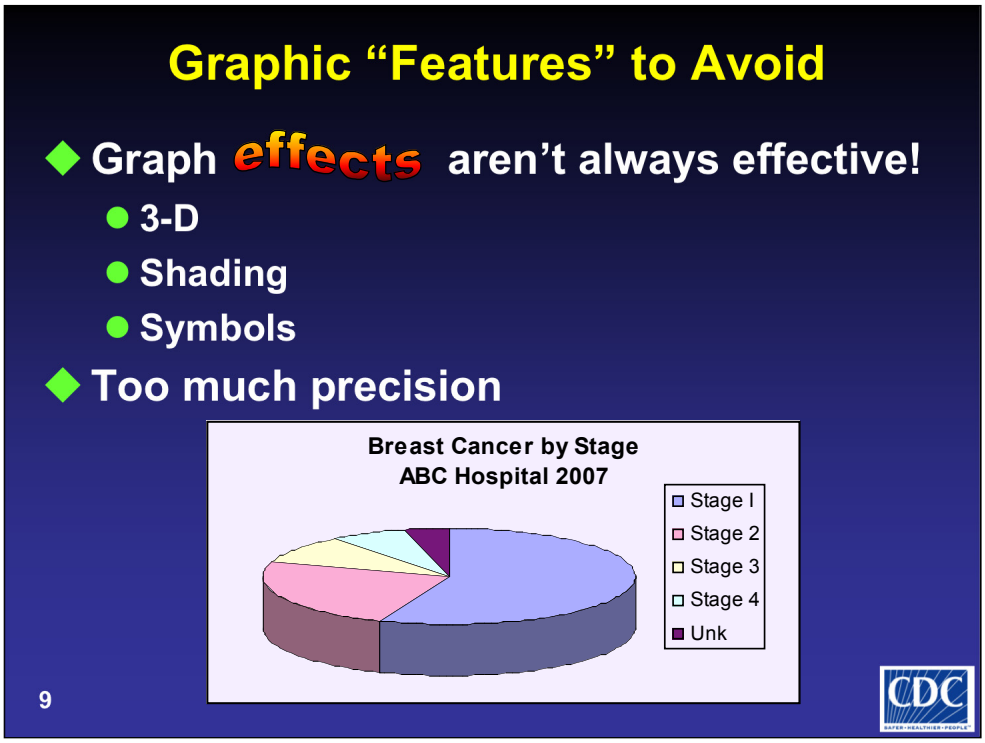
•If you chose a bar chart, and there is a relationship between the bars, group them together. For example, a study of the stage at diagnosis for three different years of kidney cancer could be grouped into three sets of bars by yea, with spaces between the years to allow the eye to adjust to the point you are making.

•The grid is the axis count of how you are measuring your units. If your graph is complicated, you may want to set the axis to show a line at every 20 units (instead of every 10) to give more open space between the lines.

•Choose colors carefully. Your color choices may depend on the media used (PowerPoint, printed handout, or e-mail attachment). Excel allows you to change the colors of everything. If there is an element you want to emphasize within the chart, consider using a strong color or line. White background is usually easier when many colors are being used, but may be too stark for slide presentations. If you must have black/white/gray combinations, choose patterns that are easily distinguishable but not cluttered

•In a graph, you should only have 1–2 different fonts. You can vary their look by using italics or bold. They should be plain (such as Arial, Tahoma, Times Roman) to avoid clutter.

(These tips came from www.orau.gov/pbm/handbook, the *"How to Measure Performance: Handbook of Techniques and Tools"* handbook prepared for the US Department of Energy)



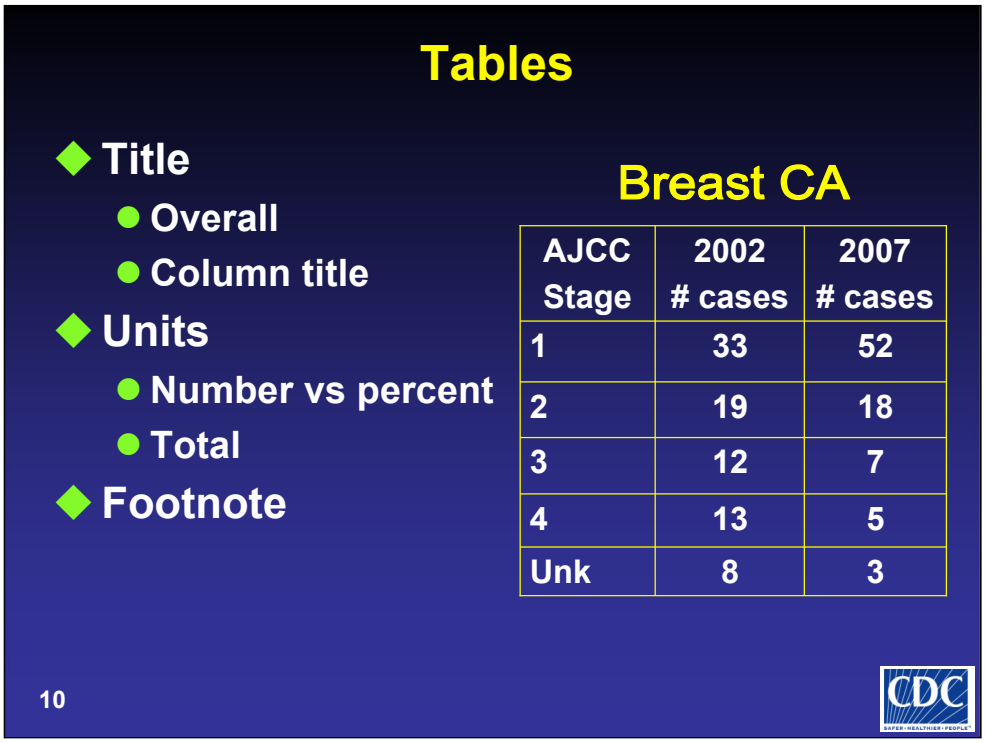
Just because a presentation program has many features, there is no need to use them all. In other words, certain effects should be used sparingly.

"3-D effects are particularly poor because no information is being added; it is difficult to read the chart values; and often the graph is also tilted to make it even harder to read the graph." *Principles of Good Graphical Design* (handbook on www.math.sfu.ca) Do you really grasp the percentage of the different stages when this graph is presented in 3-D style?

Shading, or other fancy font additions, do not make words or symbols easier to read.

Using symbols can be a good thing when they are appropriate to the subject matter. For example, use an illustration of the segments of the colon to show the frequency of disease per segment. But using the colon illustration to show the percentage of cases by stage at diagnosis would be meaningless.

You can be too precise. For example, showing survival graphs with divisions every 3 months might be necessary in some sites (pediatric or pancreas) when shorter time intervals are needed, but it will provide a very cluttered graph for the major sites with longer survival times.

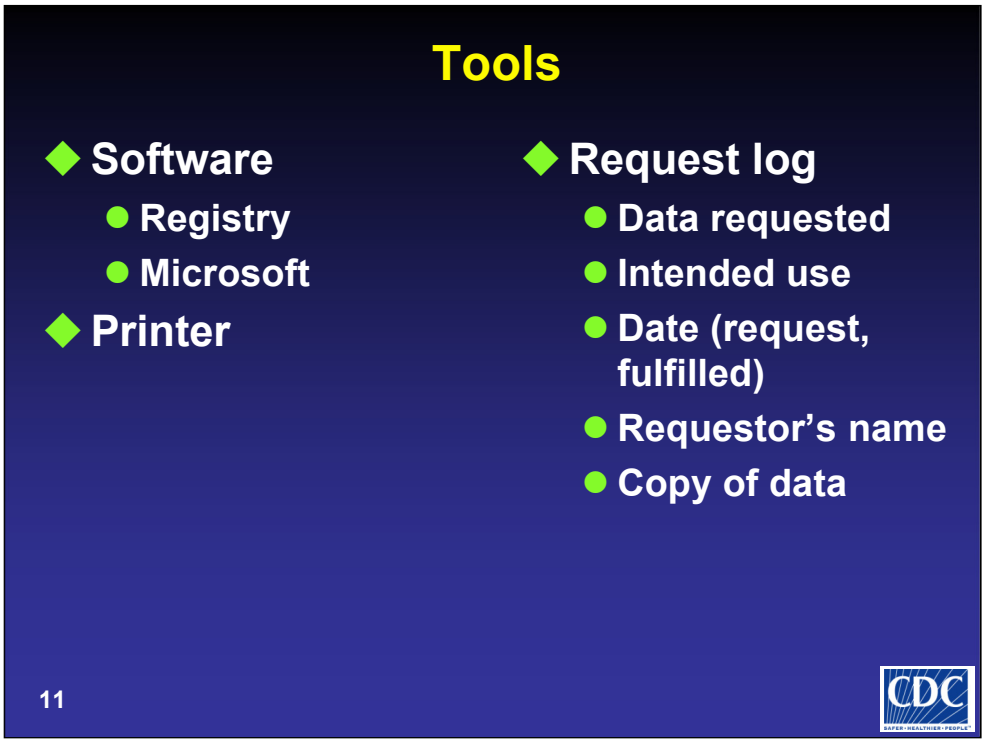


Tables do have their place in showing our data. We can use them when we have data that are not easily graphed, especially if we are trying to show a number of variables that are not easily compared such as race, age, sex or stage of a site all at one time. The tables can be created in Excel or in Word.

You should identify when you are using percentages within a table. With multiple variables, it may be easier to document using actual numbers. You may want to provide a total for each column, each row, or both, depending on what you are reviewing.

Footnotes can be used to document any exceptions to the table or any special notes about the data, and should include the source of the data.

This community hospital in the table implemented a bi-annual mammogram screening program, with the result that it appears breast cancers are being caught at an earlier stage. For space on the slide, only 2 individual years are shown (first and last. But comparing all the years between would be a good use of the table format because that would have been too cluttered on a graph.



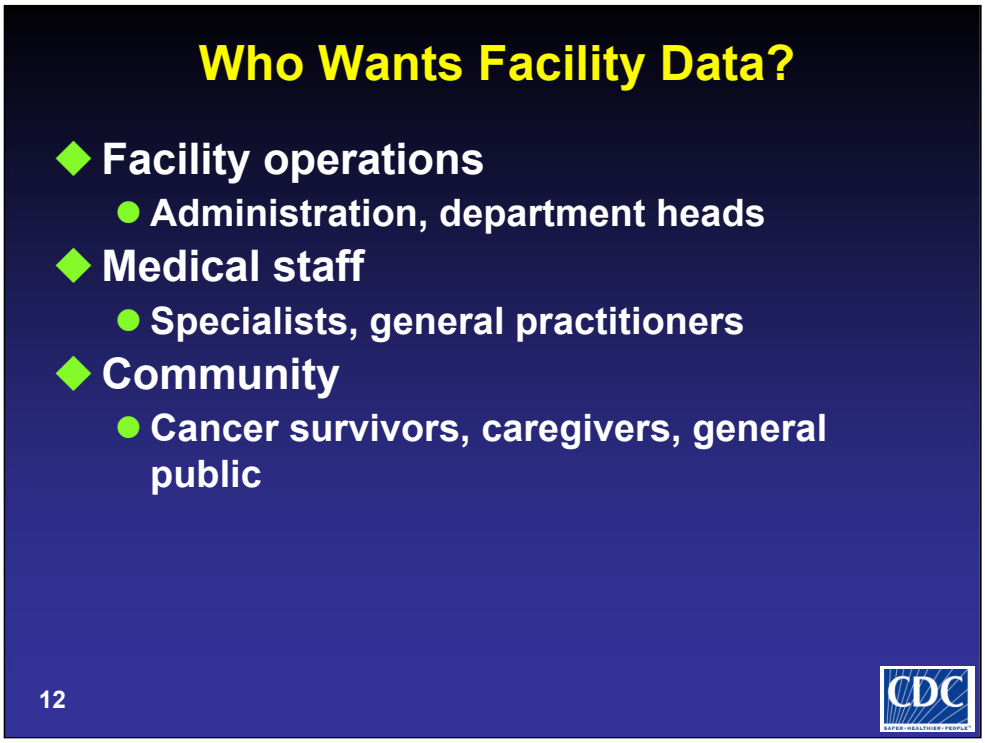
In order to generate data, the registrar must have a basic understanding of some of the processes involved. Knowing how to generate reports–both preformatted and ad hoc based on data base queries within the software–will be an asset. Understanding of Excel and Powerpoint for creating the resulting graphic is also useful. Classes are frequently offered in both types of software, and you should be encouraged to attend–possibly even within your own facility or at your next state professional meeting.

Easy access to a printer will be needed; it does not have to be a color ink printer.

One of the processes the registrar must complete within the facility is a request log of the items noted on the slide (at a minimum).

[Note to Presenter: emphasize that this is only minimal information and that the request log may contain much more information.]

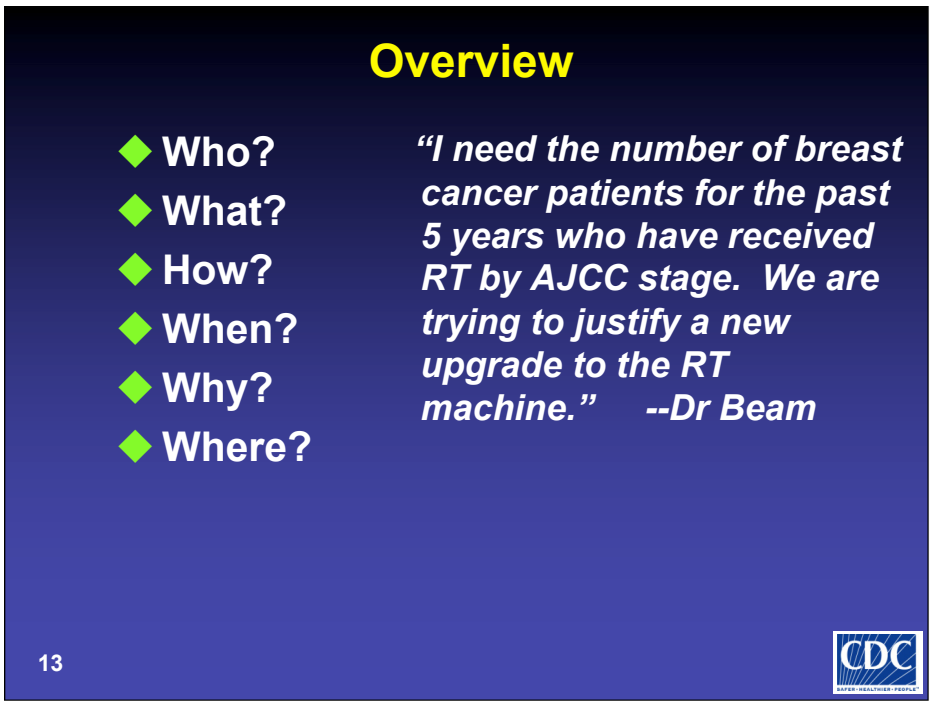
The log can be kept manually in a notebook or electronically in Word or Excel. If the facility is planning to undergo COC accreditation, this log will be reviewed by the surveyor.



Now that we know a little about how to present data, let's look at what data we want to present.

There are three groups who use facility data the most: facility operations, medical staff, and the community. Each of them has different goals or objectives for the data. We will look at them individually throughout this lecture.

The registrar must be comfortable with the data that have been gathered, including understanding the rules under which it was acquired. In addition, the registrar should be comfortable with the computer products used in the facility–usually Microsoft products such as Excel or PowerPoint. Registrars should be encouraged to take classes to acquire proficiency in using these tools.



No matter who is requesting the data, there are some basic questions that should be answered.

•**Who** is making the request? Does he/she have the authority to request those data? Do you need to get permission from someone (your supervisor, Cancer Committee, Administration, HIPAA representative, etc.) to release the data?

•**What** data are being requested? If the data request is too general, the registrar may think of multiple questions that require answers while working on the project, and have to return to the requestor or the data may not fit the needs of the requestor. If the data request is too specific, the registrar may not be able to comply (such as length of stay for all chemotherapy visits).

•**How** should the data be presented? Graph? Table? Percentages? Actual numbers of patients?

•**When** does the requestor need the data? 'When' might also include what time period should be covered. Verify calendar year vs fiscal year (for administrative requests for example).

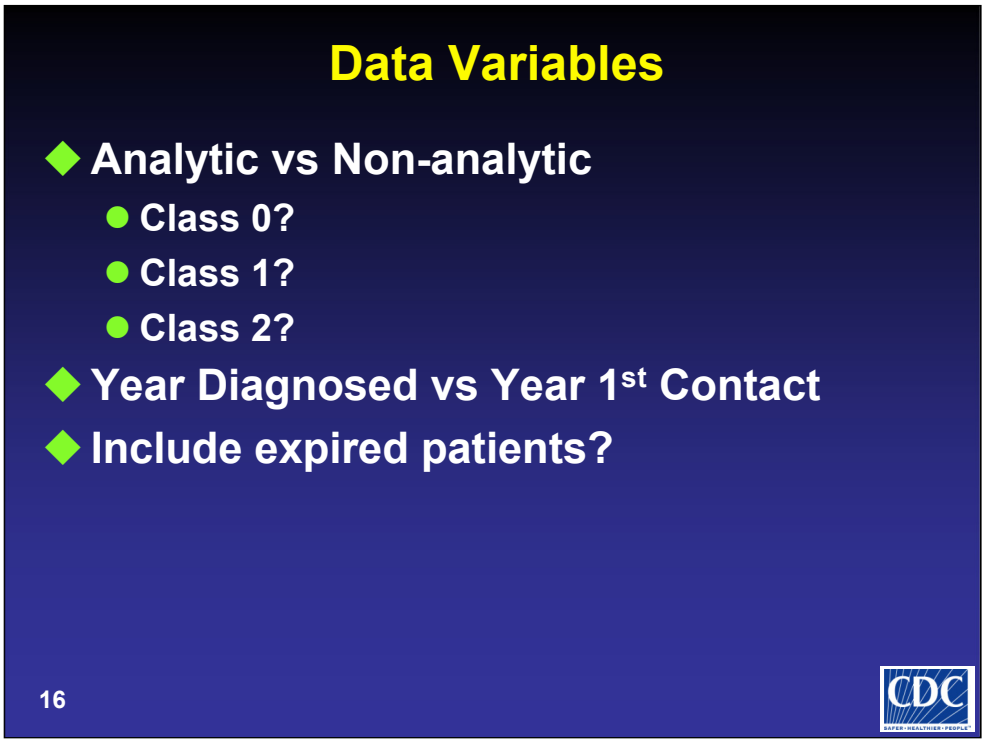
•**Why** are the data being requested? Sometimes in explaining the 'why,' the requestor will be able to document more variables that the registrar can use.

•**Where** are the data to be used? Tumor Conference? Annual Report? Board meeting?

•Although Dr. Beam's request on the slide seems quite specific, more questions for Dr Beam should arise as you think about retrieving the data. Do you want these by individual year? Do you want patients only treated to the breast? Do you want to include breast cancer patients for whom we are treating their bone mets? Do you want only patients who received beam? Boost too? Mammosite? Brachytherapy? (What does your facility offer?) Do you want a graph or a table? When do you need it? Should I copy administration?

Let’s look at the variety of data we can provide for our administration and other departments within the facility.

A facility administrator may request data to show how the facility services are being used, to see patterns in care offered, or to plan for the future. Data routinely collected in the cancer registry can answer almost all of these requests without the need for chart review.



There are certain registry data variables for which the registrar should have a good understanding in order to produce data that are reliable and useful. Choosing which of these will be most pertinent may depend on the intended use of the data.

For example, if the registry is being compared to other facilities, administration may want to review only Class 1 cases to avoid any duplicate cases being included between the facilities.

As another example, if the data are being requested to illustrate use of equipment, both analytic and non-analytic patients might be included.

Frequency Distribution

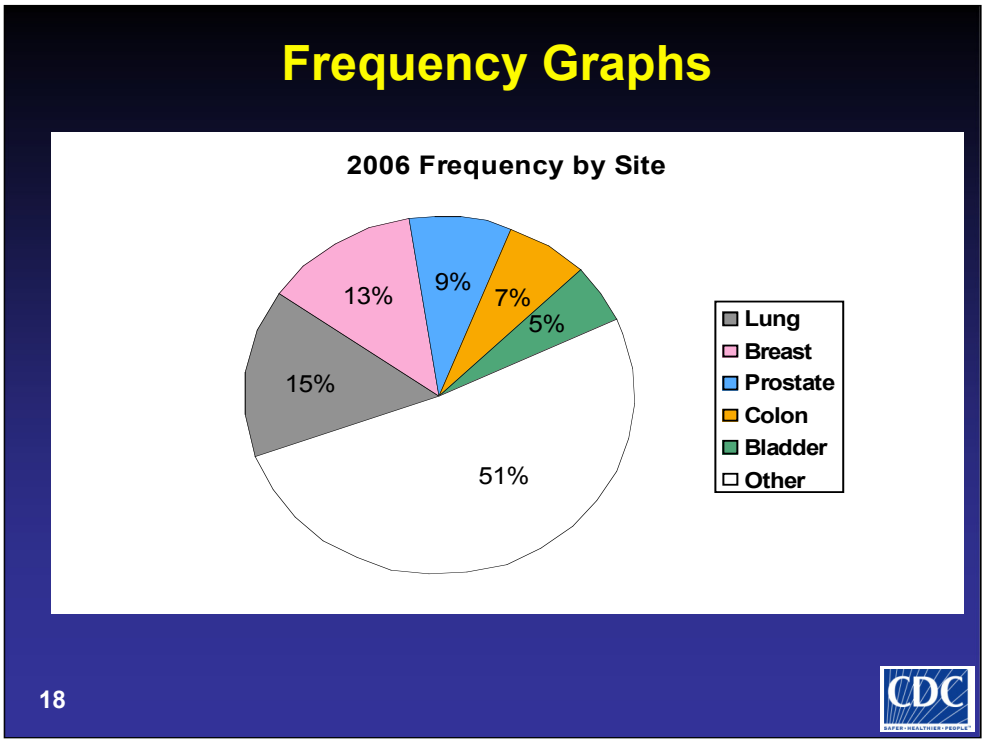
SITE CODE	PRIM SITE	TOTAL	MALE	FEMALE
C18	Colorectal	136 (11.5%)	68 (11.7%)	68 (11.4%)
C34	Lung	189	108	81
C50	Breast	159	3	156
C61	Prostate	110	110	0
	Other Sites	587	297	290

17

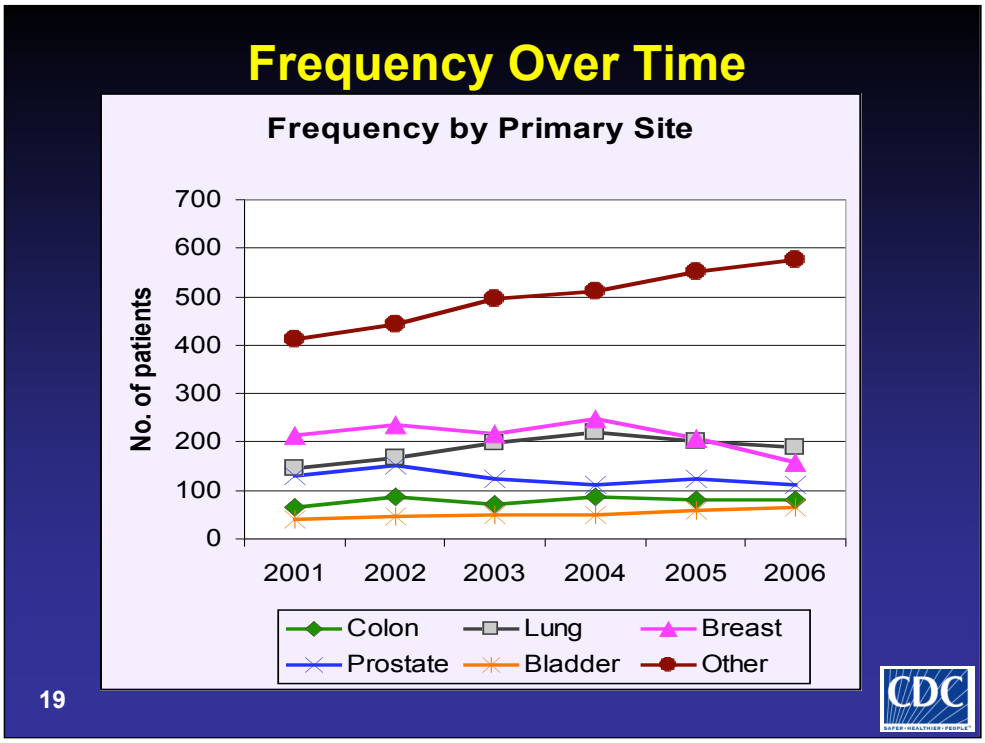
For ease in reading slides, throughout this lecture we will look at limited sites. The registrar can include much more data in reports run at the facility.

Tables can be easy to read if they are kept to a limited number of columns. Think about the intended audience for the information. If this table is intended for administration, do you need to include the site code? Is the table as simple as possible? For example, percentage of the total was added to the colorectal row alone for demonstration purposes, but would it help if the percentage was included for each cell in the entire table? Is it understood that the percentage of males is from the total of males, not the total of all the patients?

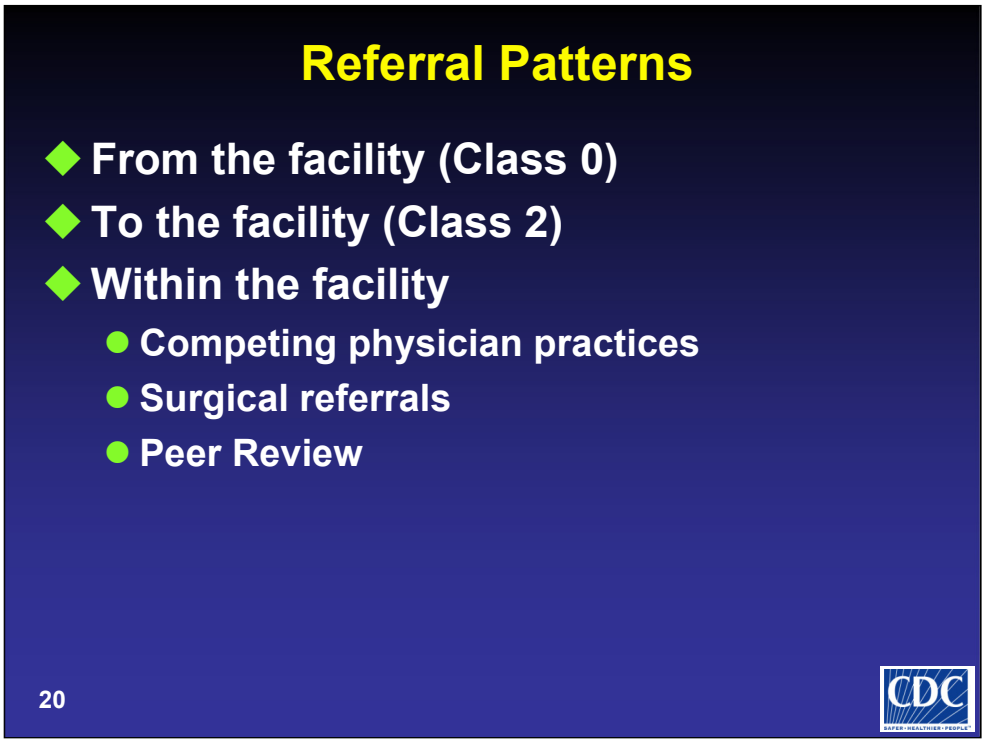
Was this frequency for analytic patients, or total patients? Remember to identify the “pool” of patients from which the table was extracted.



Does knowing the actual percentage of each of these “slices” add to the graph? Would the actual number of cases be a better piece of information? Would the best information be a combination of both?



Frequency distributions alone are not always the entire story. In this facility, the program appears to be growing; at least the “Other” category is rising. But what is happening to breast cancer at this facility? It shows fewer cases in 2006 than in 2001. Have services or physician practices changed?



Administration will want to know when patients are directed or choose to go to other facilities, and why, if it can be explained. Class 0 cases may be monitored for trends to share with a physician recruiter. Facility planners would be interested in types of new services to consider in the future.

Also, knowing where patients come from can be of benefit in resource and services planning. Are patients coming from outlying facilities? What about intra-network facilities for specialties offered only on one campus?

Within the facility, there can be physician peer pressure to refer within certain groups. If your facility has competing groups, administration may want to see the patterns of referral. Be careful with this type of data. There may be rules in your staff bylaws or other resources within the facility regarding whether physicians can see data from other physicians.

Peer review committees may need data about referring physicians. This type of committee is protected by privacy laws relating to discussing individual physicians, and how they practice medicine. It is possible that your cancer committee can also conduct peer review, but this should be verified. If the cancer committee is not a peer review committee, this information must be referred to the appropriate protected source.

Referred To (Class 0)

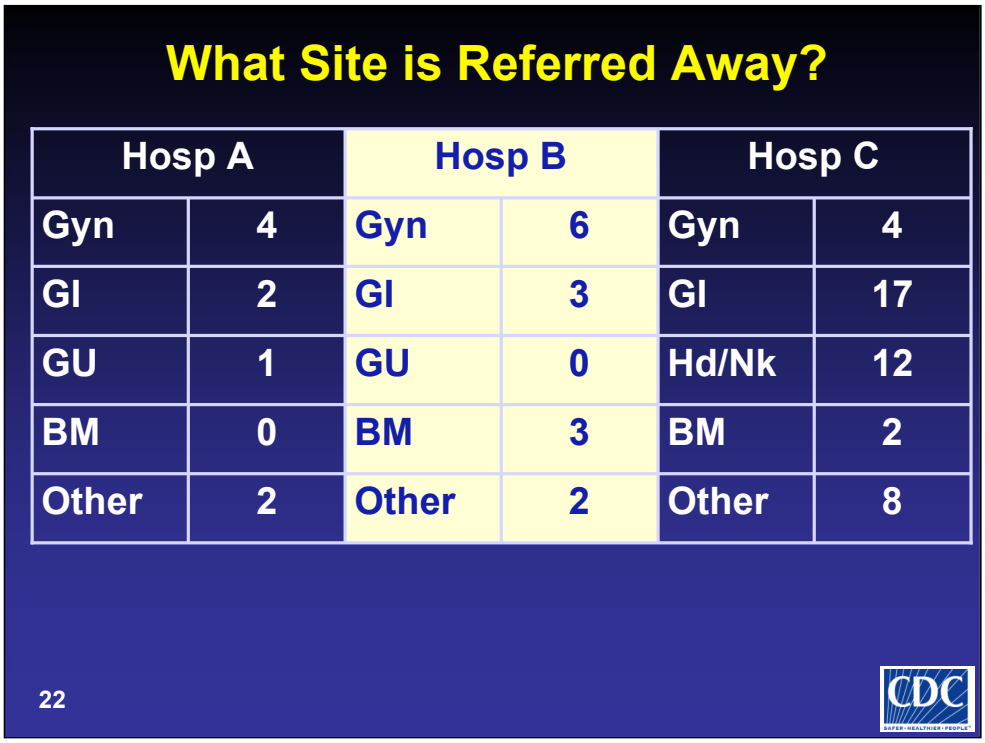
Hosp	# Pt	Hosp	# Pt	State	# Pt
A	2	F	3	IN	1
B	2	G	14	MN	4
C	7	Other	13	TX	4
D	4			KS	43
E	9			OH	1
				IL	1

5435 Total patients from 2000 thru 2004

21

This is the experience of one hospital. The shaded cells on the table were the biggest competitors for patients for this facility by location. In over 5000 cases for this facility, only 2% were Class 0. There did not appear to be a large pattern by referral to a specific facility.

Some patients were referred to a tertiary care facility in another state. This was a midwest hospital where the closest university hospital was in Kansas. Mayo Clinic is close in Minnesota, and MD Anderson in Texas received patients. There were other specialty universities in other states, or the patient went to stay with relatives and chose to go to another state for treatment. Which tertiary care facilities are being utilized may be of interest to the cancer committee or administration.



However, the same hospital reviewed the facilities that were referred to the most, and looked at the type of cancers sent to them. All of the other facilities had rare: a gynecology oncologist. This may be of interest to the physician recruiter if there are plans for adding services or a women's program is being discussed.

Not too far way is a university hospital that offers specialist head and neck surgeons. There are also liver surgeon specialists and GI surgeons who can do Whipple surgeries. Tumors in these sites are pretty rare, and most community hospitals do not have these specialists. In order to maintain proficiency in these rare but complicated procedures, a physician must do a number of cases prescribed by his facility. This may be an area where the facility agrees it is less costly to refer some patients away, instead of purchasing extra equipment.

Referral Patterns

WHO IS REFERRING WHICH ONCOLOGY GROUP? (Surg refer to Gp A or Gp									
SURG GP	2006	Gp A	Gp B	2005	Gp A	Gp B	2004	Gp A	Gp B
ENT B	1	1		4	2		2	1	
ENT C	1			3	2	1	2	1	
Gen A							3	3	
Gen B				1	1		3	3	
GYN C	1			4					
Plas C							2		
Rec C	1	1		3	2	1	7	7	
Rec D	1	1		3	3		4	4	
Uro A							1		

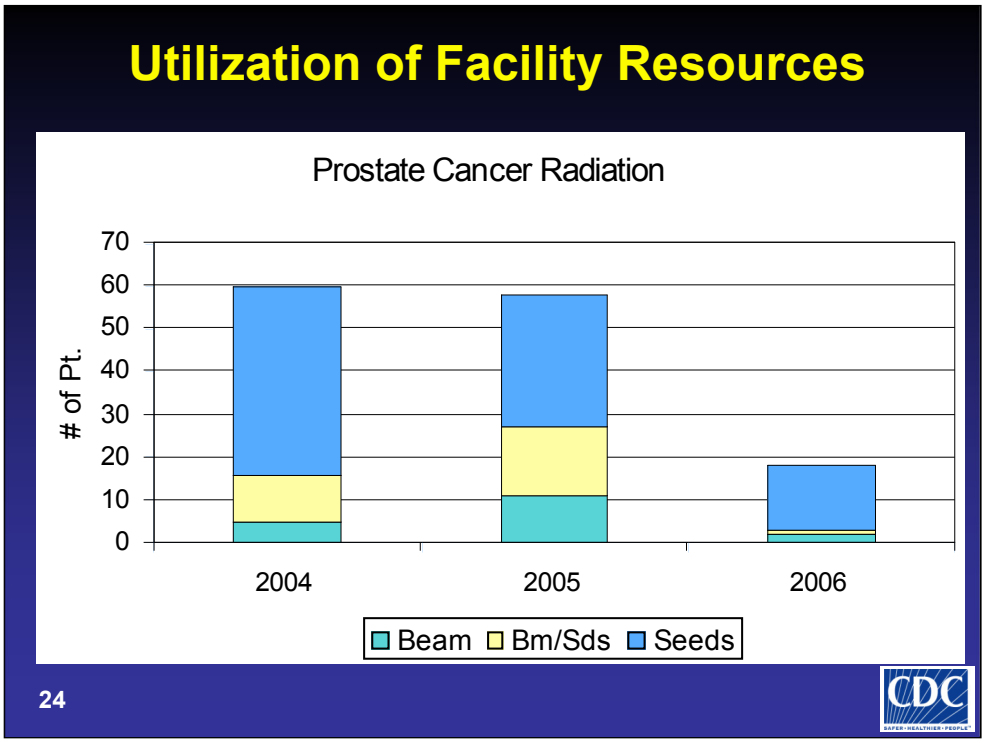
23

Administration also wanted to know the referral patterns within the facility. One of the groups of medical oncologists was building their own facility, and the question was how would this affect the hospital.

The registry reviewed patients who had a surgeon, and identified which oncology group they were referring to for a 3-year time period. The oncologist is usually the physician who influences where the radiation is done, which was another concern if the new treatment office opened.

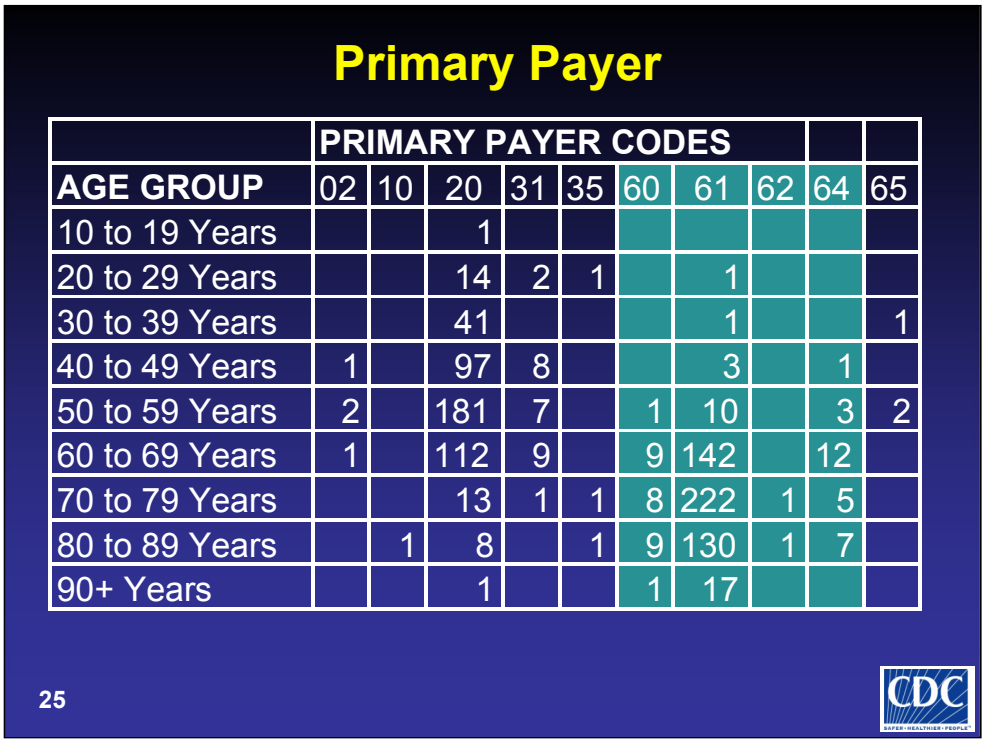
With this information, an administrator could then approach the surgeon, discuss the different oncology groups, and determine which were supportive of the facility. Surgeons may know that the referred patients received care (chemo or radiation), but they may not know where the care was given. If you're trying to keep a viable program, this could be something administration would like to influence in a positive way.

These data could also be reviewed by the managing physician according to the registry abstract. Be careful, however, if your facility utilizes hospitalists. These are physicians who just see the patient while in the hospital, and do not follow the patient after discharge; but they refer the patient back to their "regular" or managing physician. The hospitalists are usually under contract with the facility, an insurance group, or both. However, their choice of doctors may be guided by the managing physician, whose name may not be included in your registry database.



When the data on how patients were being treated with radiation were reviewed, a definite trend appeared. The number of patients being treated for prostate cancer was rapidly shrinking. Where were they going?

The registrar learned that the urologists had formed a management group and opened their own facility across the state line offering radiation. At the same time, the urologists had requested that the facility purchase a robotic surgery unit that would be used for prostatectomy (among other surgeries), and this was done in late 2005. The facility is still seeing about the same number of prostate patients (which would be reflected on another graph), but they are now frequently being treated with the robotic surgery instead of radiation.



Administration was interested in the types of insurances used by cancer patients. In particular, how many cancer patients had some form of Medicare for their insurance, especially those who were younger than 65 years old. As expected, the majority of patients were over 60 years old, but there were some in the younger groups. If the question is specifically about those younger than 65 years old, the registrar should go back for the patients in age range 60–69 and subdivide that group into 60–64 and 65–69, possibly running a separate report by age for that subgroup to get the best data.

Before handing this to the administrator, the registrar would want to correct the headings to titles, not the code numbers that we use in *FORDS*. The primary payer codes 60 through 64 include some form of Medicare. These could either be lumped under one heading of Medicare, or the codes could be individually explained just in case the administrator wants very specific information. For example, Code 62 is Medicare through Managed Care Plan, while Code 64 is Medicare with Medicaid. The administrator might want to know that in case he/she would prefer that category lumped with the Medicaid column.

This table is rather large, and might be better split into two groups of Non-Medicare versus Medicare. If the request was for all of the specific types of insurances found in the database, this is what you would be dealing with. It may be important to know that there are a large number of patients who had non-Medicare insurance (Code 20 for example). This is an example of when knowing why the data was requested might help in deciding how it is displayed.

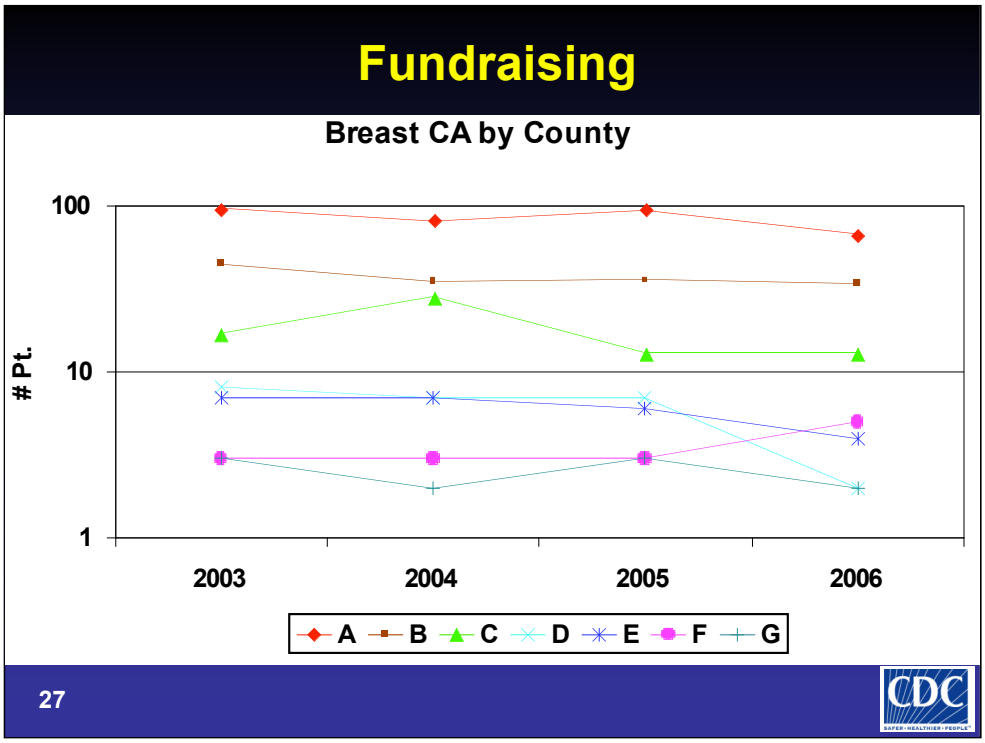
In the category of oncology staff recruitment, registry data can be used to justify the need for more physicians, nurses, or even registrars.

Physician recruiters may be interested in the frequency of cases by site. Is another general surgeon, pathologist, or radiation oncologist needed? Looking at how the program has grown over time (and in what areas) may inspire them.

Nurses may have to be recruited for education positions both in chemotherapy training and radiation management. According to the American College of Surgeons Commission on Cancer Standards, some cancer program category levels are required to have 2% or more of their analytic patients accrued to clinical trials. Looking at the volume over time may justify the need for an OCN (oncology certified nurse) with experience in clinical trials to assist the physicians, even if the facility belongs to a COP (Community Oncology Program) group.

Other technical expertise could be needed. Radiation techs, pharmacists, physical therapists, and others may be recommended based partially on the registry data.

Registry recruitment is the best use of our data. Just knowing the total number of cases each year may not be enough. The older the database, the more patients are requiring follow-up. And the more lost patients there are, the more time this may take. Registrars may need to consult the *Salary and Compensation Considerations for Cancer Registrars (2007)* from the National Cancer Registrars Association for assistance in explaining the need for more help.

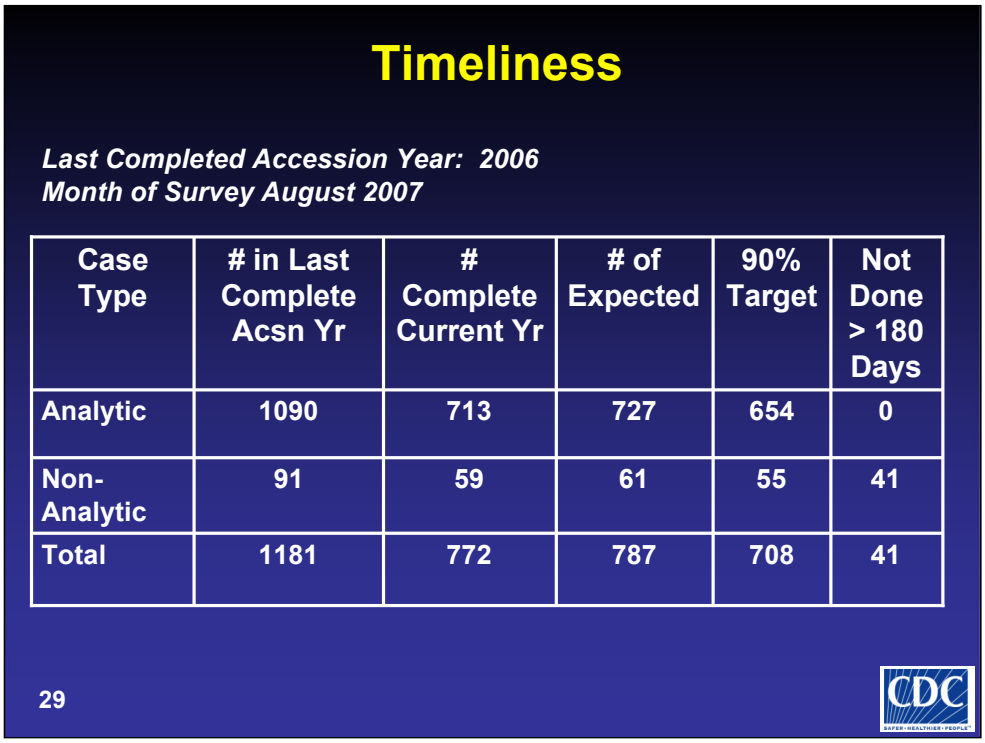


This facility was applying for a grant from The Susan G. Komen Foundation for a breast cancer project. The majority of patients seen at the facility came from the three counties within the city limits (A thru C). But the emphasis of the grant was on the outlying rural areas, and this facility was also caring for patients from those counties (D thru G). The ability of the facility and its cancer registry to supply numbers from those counties with plans for more interaction with those counties was a winning point for this grant.

Do you have someone on your staff who can write grants? Can you learn? This is a valuable source of funding for new or smaller projects that may not be approved in the yearly hospital budget.

Note that this is a logarithmic graph. When your data is disproportional with a few categories having the majority of the data, and you still want to illustrate the smaller categories, consider using this type of graph.

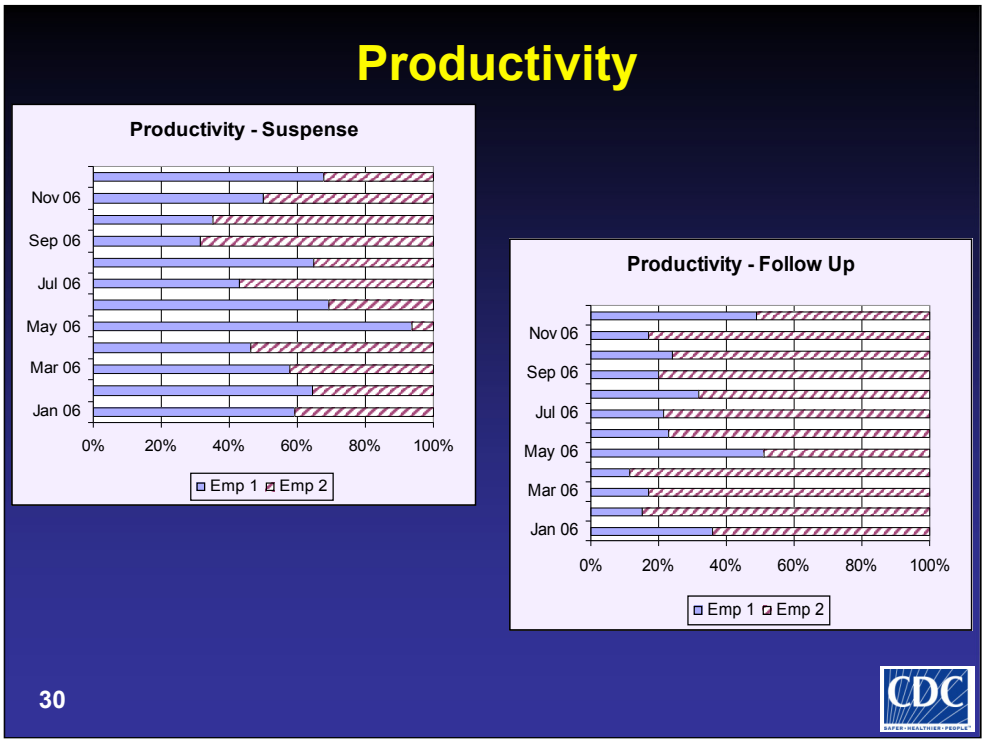
Both the registrar and the registry manager could be interested in a variety of reports that demonstrate competence and quality.



The registry software may generate a pre-formatted report that reviews the number of cases completed with the 180-day (6-month) standard set by the COC and NPCR. This is a sample of what it may look like.

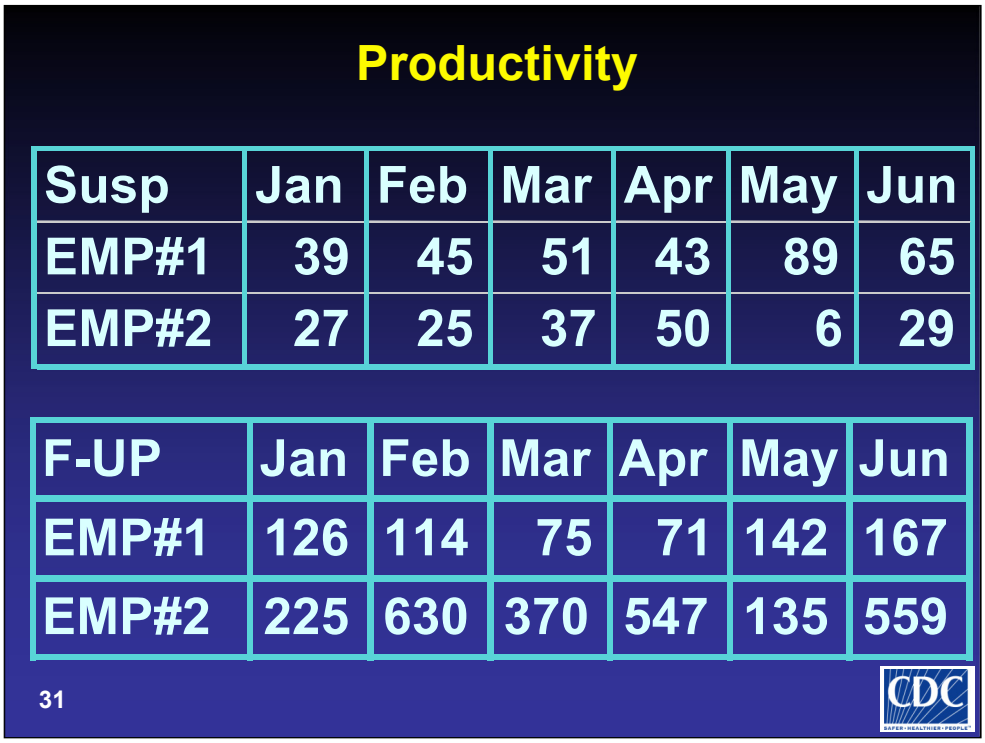
The software for this registry takes the number of cases completed in the last accession year (2006) and divides it by 12, to get an estimate of the number of cases expected per month [1090/12 = 90.8 per month for analytic]. The third column is the number of 2007 cases that are already complete within the registry. The fourth column is the number of 2007 cases expected to be completed in the registry (90.8 x 8 months for analytic row). The fifth column takes 90% of the fourth column (90% x 727) for what the COC expects to have done under Standard 3.3. The last column reports the number of cases that are still in suspense and incomplete. Looks good for analytic, right? The only problem is that the registry does not enter case status when putting cases into suspense, so the computer assumes “9” (unknown) and therefore non-analytic. But the last column can at least tell you how many outstanding cases there are left to be completed for the first 8 months. It looks like this registry would pass the standard 3.3, because more than 90% of the target cases are completed. We only looked at the analytic because that is what is required by the COC. Your central registry may also want data on the number of non analytic cases that are incomplete. Does your software have a similar report?

You should have a discussion with your central registry about how to handle outliers (in other words, the 41 incomplete cases). A good example is the breast cancer patient who does not have all of her treatment started within 6 months. Does the central registry want the case submitted at the time of diagnosis and the registry to re-submit when more data is available? This may cause the central registry to treat the second submission as a duplicate case if it is submitted electronically. Do they want that additional treatment data on a paper form, or do they recommend that the registrar wait until the case is complete prior to submission?



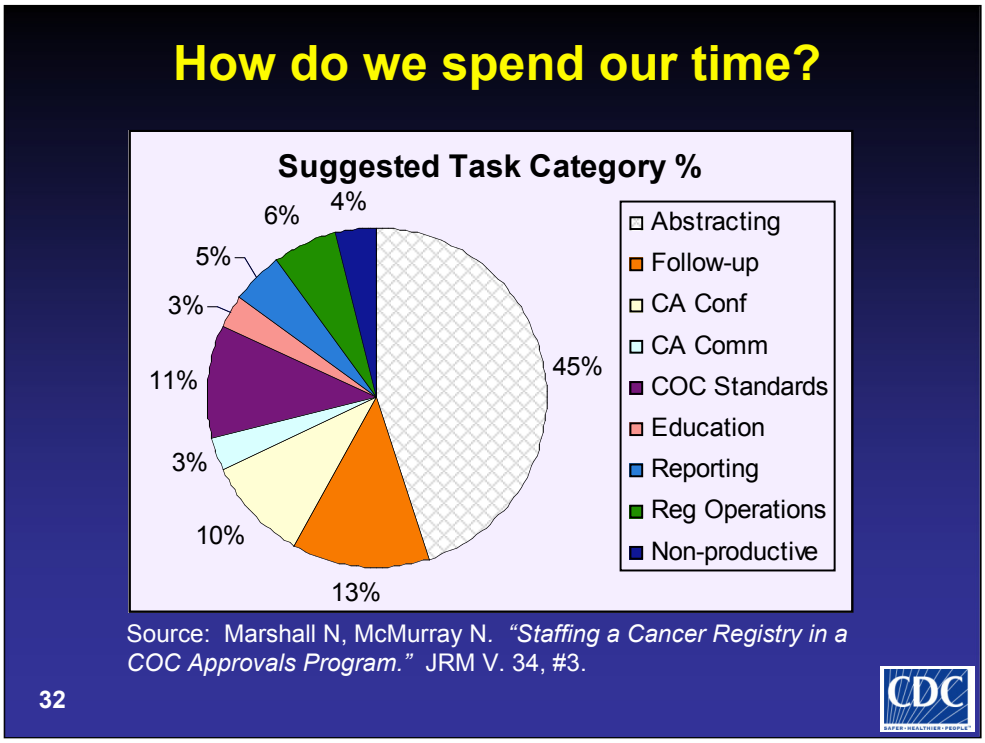
This registry has two CTRs. Comparing these graphs would make it appear the workload is fairly even. Employee #1 appears to do more of the casefinding, while Employee #2 appears to do more of the follow-up. Is that a fair division? Maybe not. How is the casefinding done? The majority of casefinding here is done by picking up copies of the path reports and entering the few data items that create a suspense case. Altogether, it takes less than one minute per case. There are approximately 75 new suspense cases per month.

In contrast, followup is done on approximately 600 cases per month. It requires the registrar to look through the Master Patient Index (MPI) for new dates, read the record of any new admissions, do the data entry, and then send letters for those not found, as well as data entry of those letters when returned. Follow-up takes 13–15 minutes per case. If you are presenting this productivity data to the registry manager, who may not be a CTR, what else would you want to document?



This is some of the same information as the previous slide showed in the graphs. But the story is a little better understood by seeing the actual numbers. This may be a scenario when a table actually shows data better than the graph. Of course, it could have been the choice of graphs. The graphs on the previous slide were illustrating who did what percentage of the total work. The bars could have been set to show actual numbers, but as we can see from the table, the bars would have been radically different within the follow-up, and it might not have been as easily understood as the table.

Each facility sets its own productivity standards on what is expected for major job tasks. Maintaining data on productivity requires good definitions and constant monitoring.



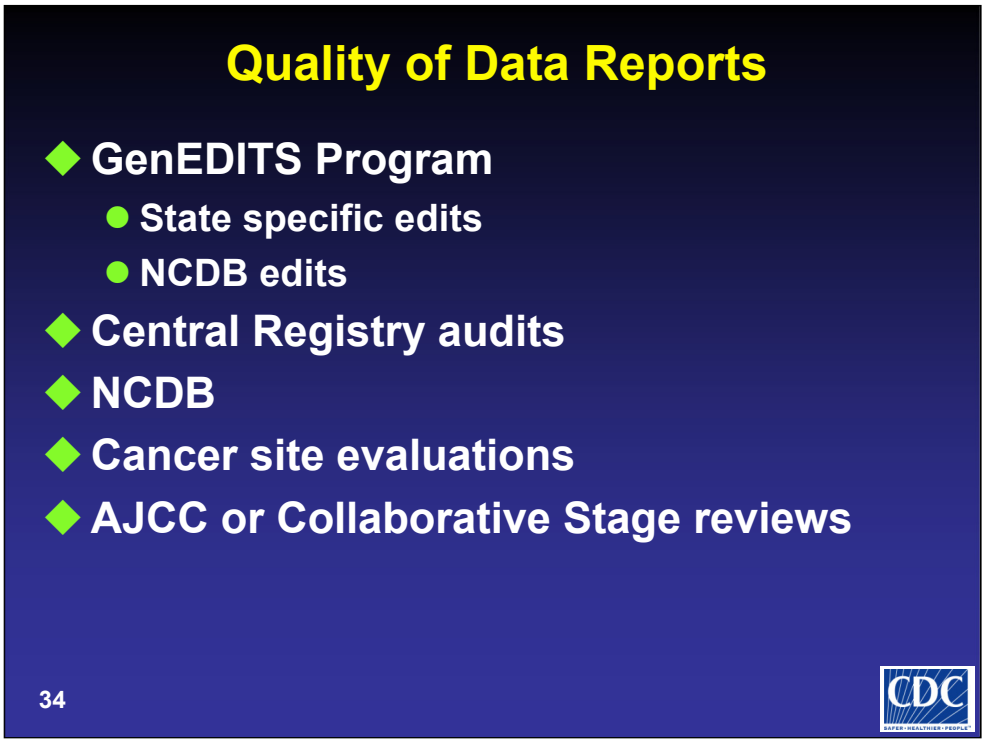
An article published in the Journal of Registry Management discussed the amount of time spent on various registry tasks. This article was based on a time study completed by 29 registries. Abstracting includes casefinding in this diagram. Many of these tasks cannot be divided into a measurable standard, such as conference preparation or reporting. To get a total picture of the workload within the registry, the manager will need other means such as reviewing report logs, documentation of number of cases presented at tumor conference, etc.

If the registry/registrars are struggling with the amount of work, is there any help that can be given? Could a volunteer be trained to handle repetitive jobs such as the follow-up mailing or looking up patients?

Is it time to ask for more technical help within the registry, such as hiring a part-time clerk or even an additional registrar? Should an outside service be contracted to help the registrars become timely again?

Quarterly reports are a good way to keep track of registry productivity. These may be requested or required by the registry manager, or they can be used to document the need for more staff. Administration may be interested in knowing the number of patients remaining in the suspense file, or the number of patients seen by the Radiation Therapy department. Cancer committees may want to know how many cases have been presented at Cancer Conferences.

What could be reported? Keep track by month of the number of cases completed. The registry computer is probably doing this for you with a "Completion" date built into the software. Follow-up may be reported as number of cases found or lost, or as the percentages compared to the COC standard. Be sure to document any special events, such as state or national association meetings, participating in screenings, or Survivors Day events. Anything that the registrar participates in that may have altered general workflow expectations should be documented.



How can the registrar check the data within the registry? GenEdits is an edits program that allows specific edits to be run on cancer data, such as state specific edits and NCDB edits.

Running state specific edits is encouraged—if not required—by most central registries prior to submitting data to them. Ask your state registry to provide you with state specific edits.

In order to meet Standard 3.7 of the Commission on Cancer, any data submitted to the NCDB should pass NCDB edits 100% prior to submission. This is another opportunity to find and correct errors.

If the central registry has audited any part of the registry (casefinding, abstracting accuracy, etc.), this should be reported to the registry manager as well as the Cancer Committee.

When the Cancer Committee does a site study for the annual report (or its equivalent) in your facility, this is an opportunity to review the documentation in the abstract against the medical record, especially the site, histology, and staging fields.

There are many AJCC fields that could be cross-tabulated for quality measures. For example, reviewing the size of the tumor against the “T” category in some sites. Reviewing the number of lymph nodes positive against the CS derived “N” category is also a possibility.

Note to trainer: This might be a good opportunity for audience participation. What QA reports have they run?

Wikipedia discusses marketing as a social process which satisfies consumers' wants and needs. Health care generally is concerned with patients' needs for diagnosis, treatment, and maintenance. How can the cancer registry aid in that process?

In today's health care world, there is fierce competition. Not only are hospitals competing against each other for patients, but there are now freestanding facilities in the competition. Insurance companies are looking at facilities and their outcomes as part of making contract decisions. A website, www.strategichealthcare.com, lists 17 different topics that their magazine covers. Those on the slide are some for which the registrar can offer data.

We can use marketing with wellness and prevention information. We frequently have resources that facility marketers do not have, or may not understand as well as we do. Using our data for early stage cancers and recurrence rates could show patients that maintaining regular health care is wise.

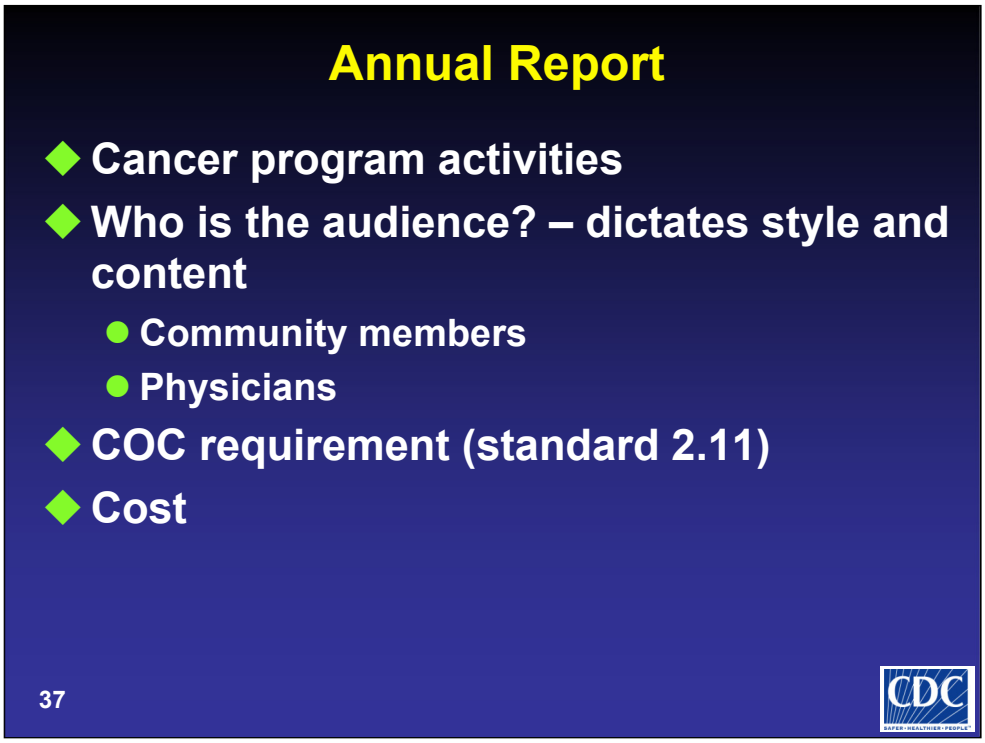
Does your facility offer a specialty that is not available elsewhere in your community, city, or state? Showing the frequency of use of that specialty, or the area where patients come from by county/state for that specialty would be a good use of data.

Care management could include the number of breast cancer patients treated with lumpectomy, prostate cancer patients treated with robotic surgery, or abdominal cancer patients treated with laparoscopy.

Does the registrar help with community screenings or assist those who are planning them? Creating graphs for them is one way to use our data and help them with their message.

One method of report cards for the registry would be the annual report, which we'll review next.

Note to trainer: Another area for discussion and idea-sharing, what reports has the registry run for the marketing department?



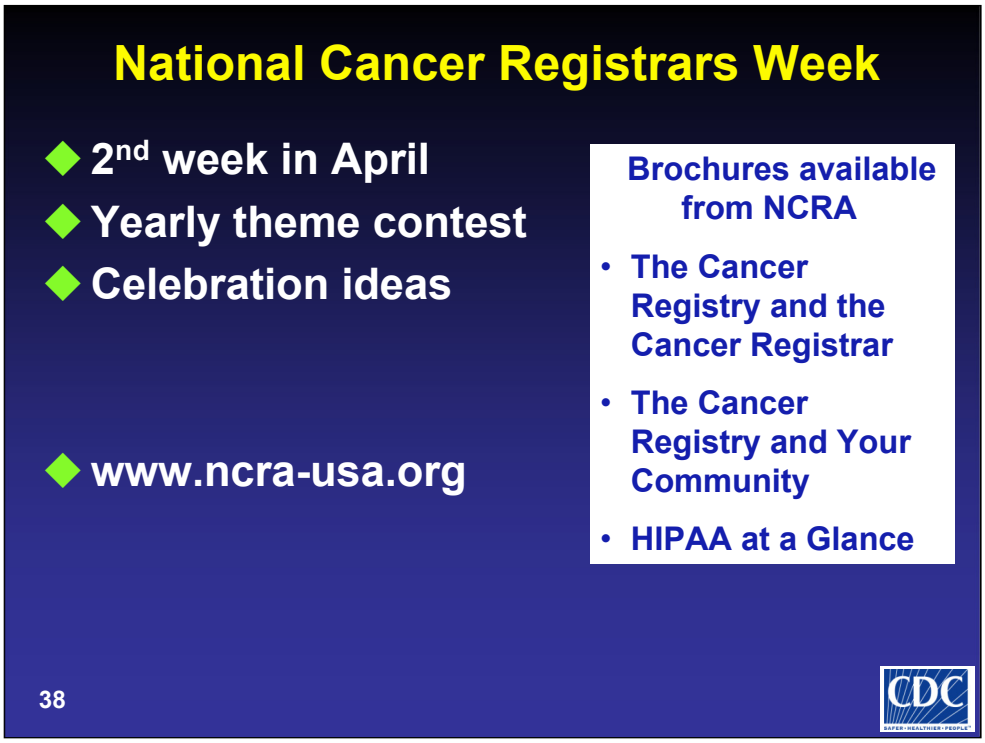
The cancer committee or the facility may require an annual report to summarize the facility's experience with cancer over a designated time period.

If the facility/committee has decided there will be an annual report, one of the questions to be answered is to whom the report should be directed. There are different styles of writing, and different information that would be included for a community audience compared to more scientific information that might be used for physicians. The community report may include many pictures, patient stories, and generic disease explanations with fewer medical words. If you are looking for suggestions on how to write for the public, try visiting Web sites by searching for "writing" and "general public". There are good suggestions and examples at www.writing-world.com.

A report for physicians will include medical terminology and more involved graphs.

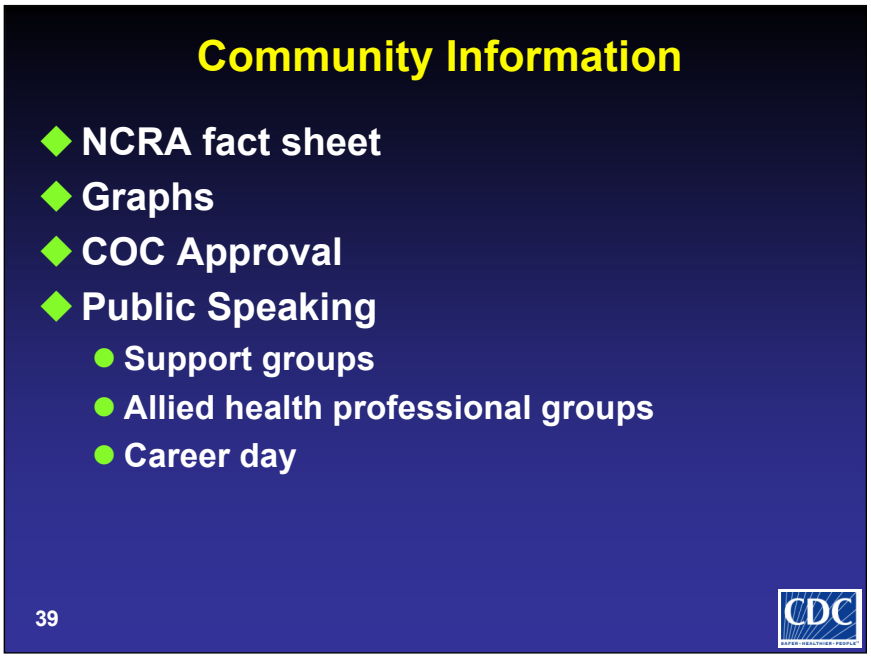
COC approved facilities require that the cancer committee analyze patient outcomes and disseminate the results of that analysis. An annual report is one way that can happen.

While the registrar may not influence the budget of the annual report, she/he should understand that the budget is an influence on the style of the product. *Cancer Registry Management: Principles & Practice*, Chapter 28, has many suggestions of components that could be included in the annual report.



National Cancer Registrars Week is our opportunity to celebrate the cancer registry profession, as well as illustrate cancer information about our facility. It occurs annually during the second week of April. There is a yearly theme contest for NCRA members, with idea submissions due in January. Prior to NCR Week, NCRA members receive a poster illustrating the year's theme and can use the poster to decorate their area or other areas within the facility.

There is a listing of ideas from other registrars of how to celebrate the week. You will want to plan ahead for the most fun and education. You can contact NCRA to offer your ideas. The NCRA website also has multiple brochures and fact sheets that you may request to educate your co-workers or community about our profession.



NCRA has a fact sheet entitled “The Cancer Registry and Your Community” that documents how cancer registry data has made a difference with examples from some states. Work with your central registry to produce information specific to your state or community, and show how registry data has helped cancer patients.

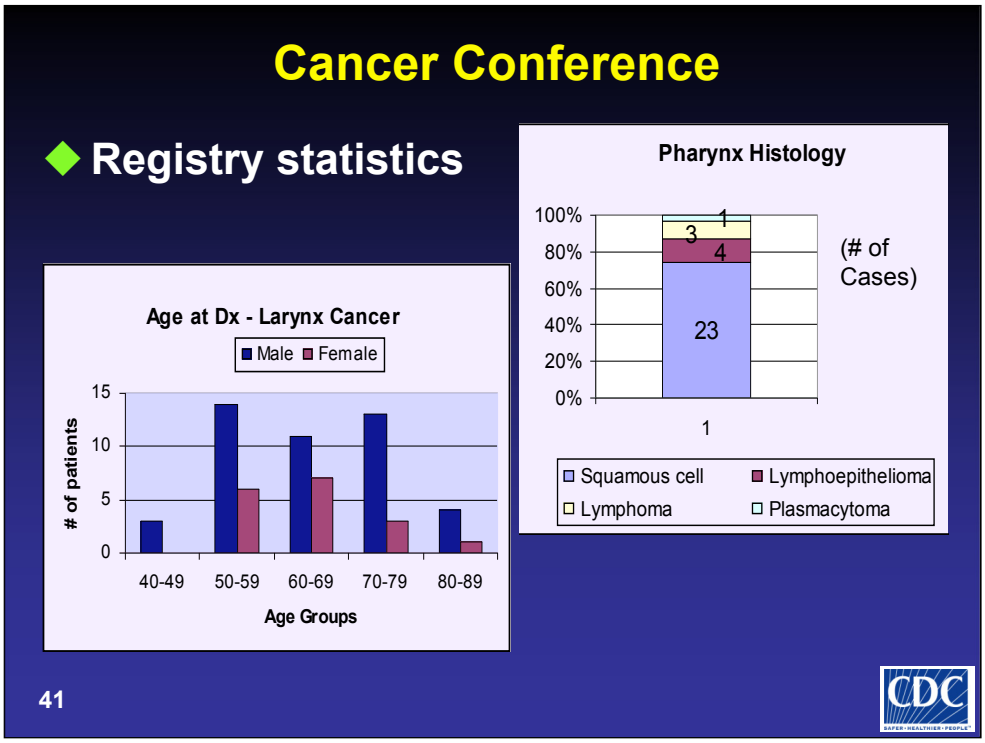
Creating graphs about the data within your facility may help the public understand the role of your facility in healthcare within their neighborhood. We all know someone with cancer. What is being offered at your facility?

Any time your facility undergoes COC survey and receives approval, you will receive a publicity kit to notify the community. You may use it as is, or enhance it with more information by working with your Public Relations Department.

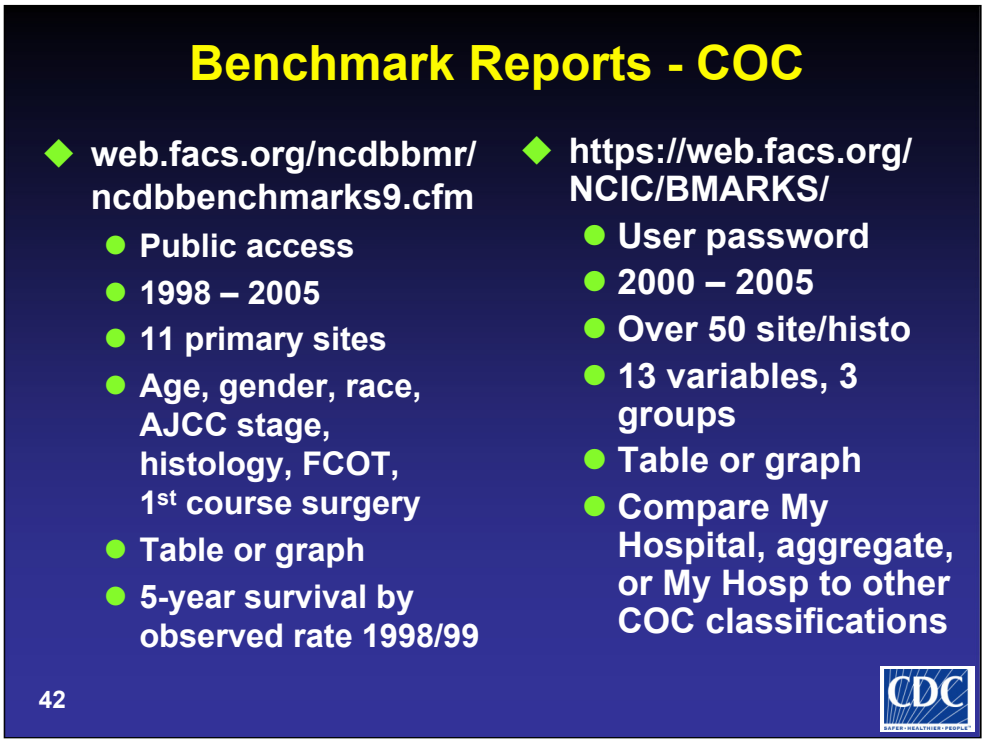
Have you considered public speaking? Whether it’s informal chatting with a support group about what type of data we gather and how it’s used, or a formal presentation at your local high school career day, you could be making a difference in the understanding of our profession as well as cancer as a topic. How many allied health professionals (pathology secretaries, oncology nurses, therapists) understand what you do? On their website, NPCR offers “Quality Cancer Data Saves Lives - The Vital Role of Cancer Registrars in the Fight Against Cancer,” which is a slide presentation that can be tailored to last from 30–90 minutes. It is available from www.cdc.gov/cancer/npcr/registry/QualityData.

NAACCR has a speaker’s kit available on their website (www.naaccr.org) under Education Resources. Or you may want to create your own presentation. If you are speaking on behalf of your facility, always ask the public relations, legal, or another department to review your presentation for content. Check your facility’s requirements for presenting data.

Many of us wish our physicians were more interested in our data, while some of us are fortunate enough to have doctors who almost drive us crazy with data requests. What are the most common topics we should be illustrating for our physicians?



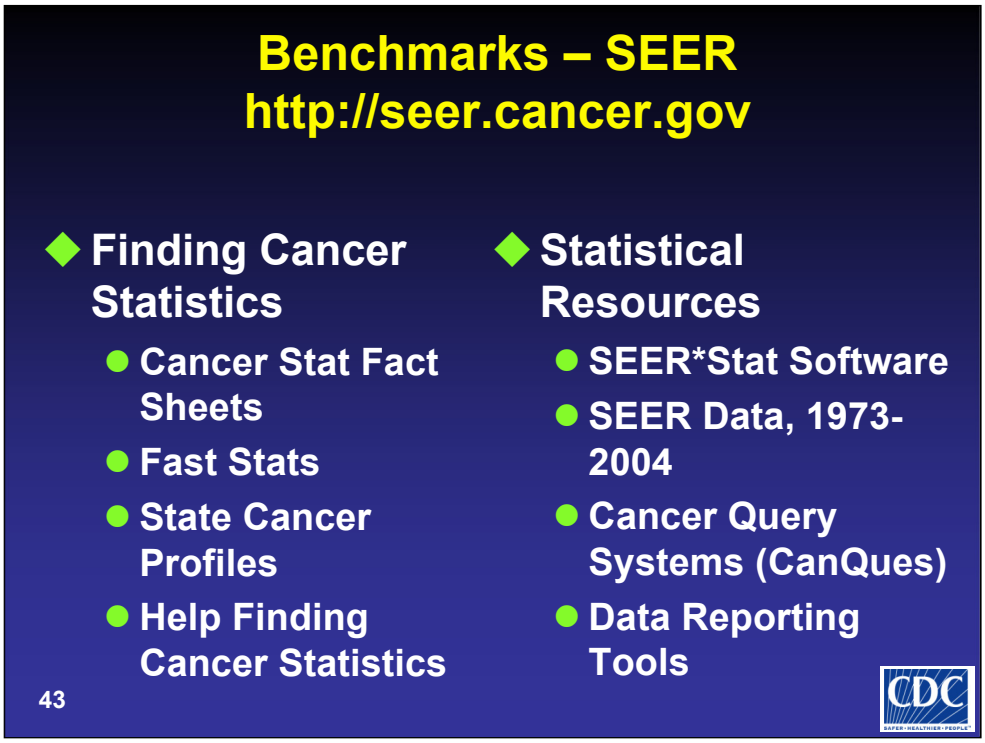
Cancer conferences are one place to provide a quick bit of information. One graph or page of information created for each conference might encourage the physicians to ask for more data. What should we show? Do you know why the cases are being presented? That may guide what information you wish to provide. Is it a younger than usual patient? Is the tumor in an unusual location? Is it a staging or treatment issue? What are the current hot topics or controversies pertaining to the site being presented?



Even if you are not working in a COC-approved program, COC data are still available to you for comparison. The Web site on the left is the public access information. Data on the eleven most common sites are available. The variables available for each site include those listed on the screen. Results can be viewed/printed in table or graph format. There is also a section where the public can access survival reports from 1998/99 cases. This area can be a little hard to find, because it is under the Accreditation heading, and then under the NCDB heading in the drop-down box.

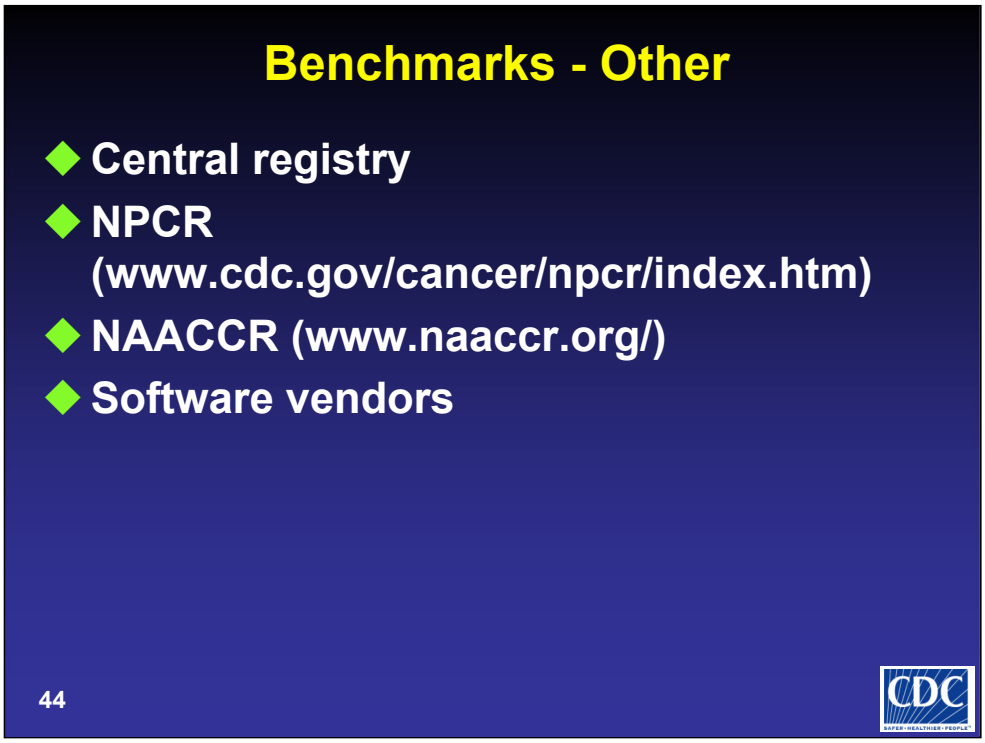
If you work in a COC-approved facility, you may access data on the NCDB website in the password-protected section. There are fewer years available, but many more sites and histologies (such as lymphoma). You can compare more than one variable. You can review just your facility, aggregate data, or compare your facility to other facilities within your approval category or higher.

There is a new section about survival reports that has over 50 sites and histologies, allows you to choose 2-year groupings (1994–1997 OR 1998–2000) and has more options of displays.



SEER has two sections on their website that can be used to create comparison reports. Quick and easy statistics may be more readily findable on the section described on the left. The bullets under the Finding Cancer Statistics are the types of reports available.

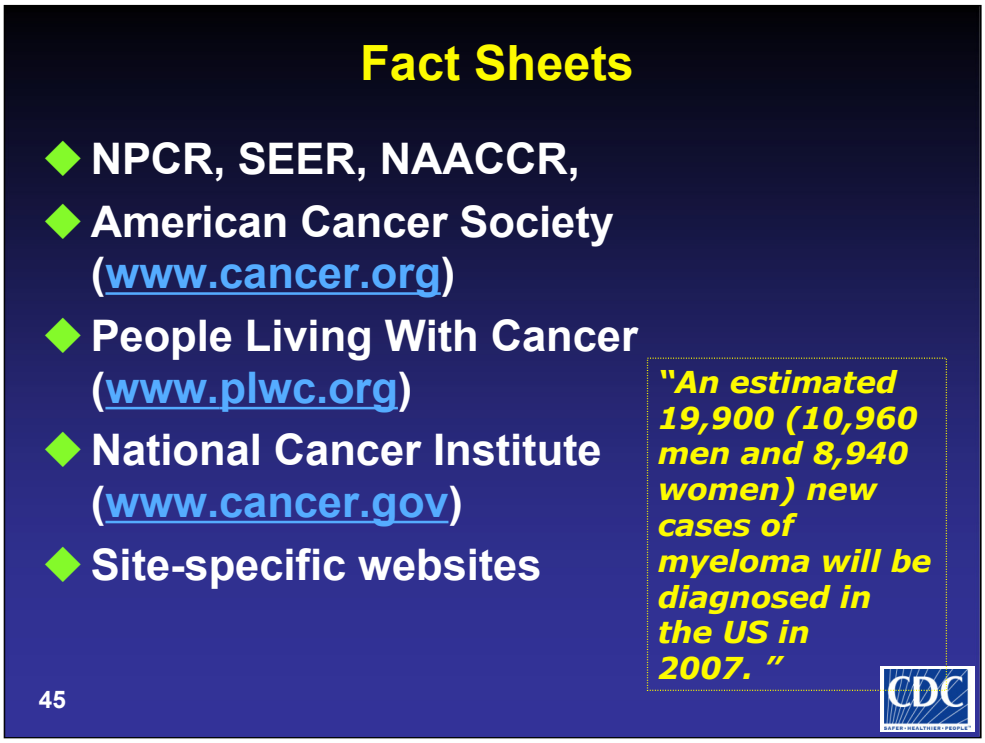
For more specific information, you will want to install the free SEER*Stat software. For example, breast statistics would be available in both sections. But if you were looking for survival on only lobular or medullary breast cancers, only SEER*Stat allows a choice of specific histologies.



There are other resources for comparison or benchmarking reports. Your state or regional central registry would be a good resource for data in your area. Many central registries have websites that are user friendly, or you may contact them with a specific request. The next part of this presentation describes the variety of ways in which central registry data are used.

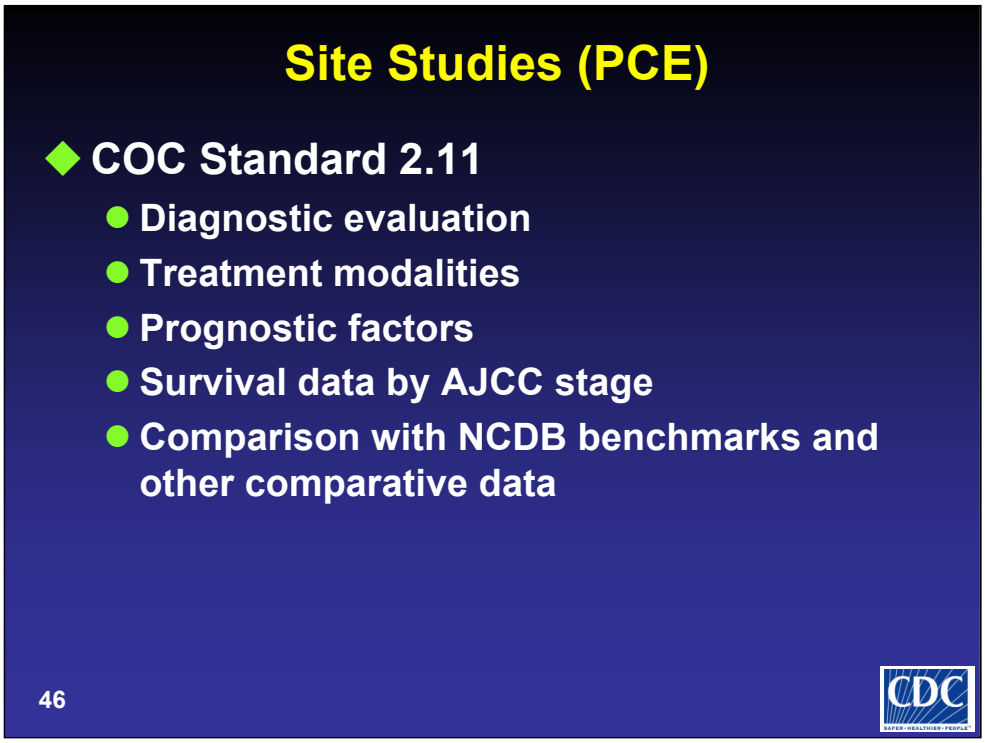
NPCR offers some data, as does NAACCR. The issue with the first three resources on this slide is that they tend to talk in terms of rates per 100,000, and a hospital or smaller facility may not be able to obtain good comparison statistics from that. But they may be great places for general data, especially for your state compared to others, or to show the statewide or national burden of cancer.

Your software vendor may offer you the opportunity to contribute data to a large collection they maintain of de-identified data. You should contact them about what is available and how you can participate.



We've already seen some websites that offer fact sheets about cancer. Four of the best, consistent, and reliable Web sites that maintain information are NPCR, the American Cancer Society, People Living With Cancer (from the American Society of Clinical Oncology), and the National Cancer Institute website.

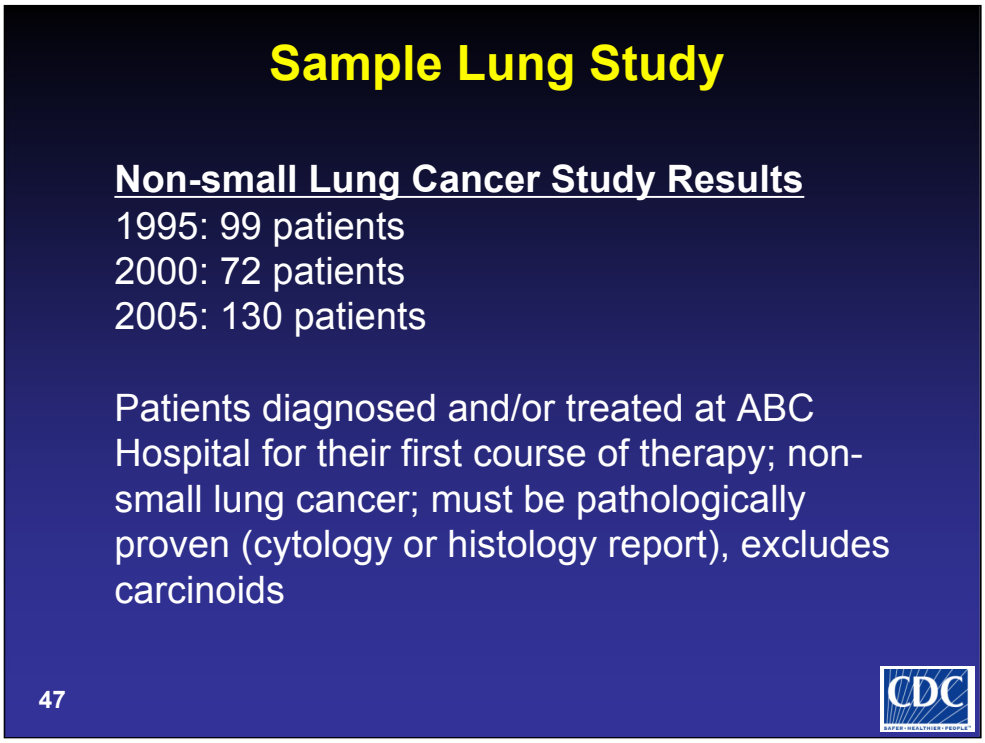
In addition, there may be a Web site created for a specific organ or body part (American Lung Association, The Leukemia and Lymphoma Society, etc.) that may offer you easily understood information.



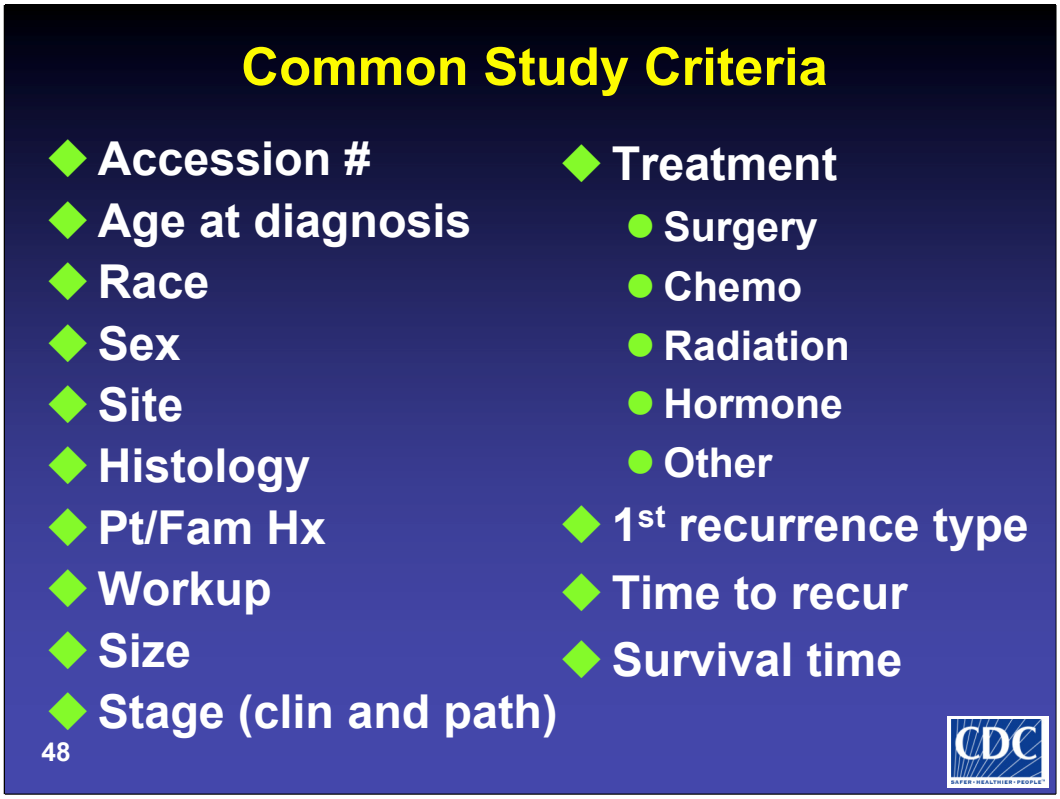
Some of the slides in this presentation are specific for COC approved programs. However, the cancer committee at any facility can create patient care studies or quality indicators. Registry data can be used to monitor quality at any facility.

In COC approved programs, the cancer committee is responsible for determining which site should be studied, although this may mean that the registrar will be participating in the decision. You may want to keep a log of what sites have been studied in the past when it is time to set the yearly goals for inspiring the committee to review a new site or revisit a site that has possible changes in treatment or prognosis. A new study may repeat a previous study so that the committee can track how well an intervention (based upon previous study results) is working. Has the outcome improved?

Standard 2.11 recommends the items listed on the slide should be included in a site study. Again, any health care facility can use its data to track quality of care.



This would be an extensive study due to the large number of patients. If that is a problem, you may ask the cancer committee to do a sample study. For example, the sample study could include the first 30 diagnosed within the year, or three cases per month. On the other hand, if most of the information that the committee wants to study is available within your database, it is just a matter of transferring data from the database into a spreadsheet, and calculating the information (percentages and counts). It might be a good idea to have a listing of what information is readily available from the registry for the committee to review. It is possible they will still want to review other information, which, will necessitate chart review.



It is best to keep track of the information according to the patient's accession number. That way, worksheets and/or spreadsheets can be taken to committee without fear of patient identification.

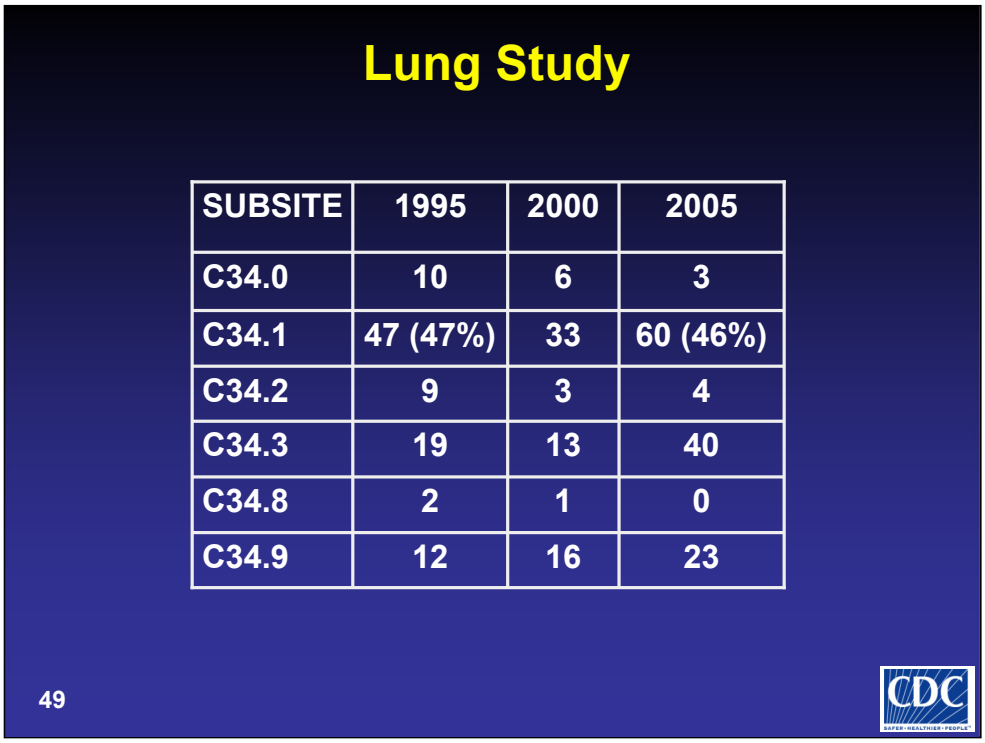
- •Age at diagnosis is usually calculated by your computer. This is also an easy statistic for which to find comparison data.
- •Depending on the site in the study, and your hospital population, you may not want or need to analyze race or sex.
- •Sites can be reviewed by subsite codes to see if any migration has occurred between subsites, but your study sample will probably be so small that it may only be a note that the physician reviewer makes in passing.
- •Histology should be reviewed prior to beginning to gather the cases. There may be some outlying histologies that should not be included and the physician reviewer/committee can make those decisions early. Also, the physician reviewer/committee may want to exclude clinically diagnosed cases.
- •Does the committee want to see the patient's cancer history? How about family history for those cancers suspected to be genetically linked?
- •Workup has changed over time, and that is one aspect that the committee may wish to review. Twenty years ago, most breast cancer patients had a bone scan, brain scan, or other scans to rule out metastasis. Now there are few scans. On the other hand, as newer tests become available (such as PET scans), showing their utilization allows the physician reviewer to comment on how workup has changed.

•Reviewing size of tumors in those sites that include size as a staging factor is a good opportunity to double-check your data. Depending on the site, you may want to include both clinical and pathologic staging, especially if it is a site that is frequently treated with neoadjuvant therapy.

•Treatment data can be tailored to the study and the site. Perhaps the lung study mentioned on the previous slide could have reviewed only those cases which were treated surgically. Prostate cancer may be studied in just the radiation patients. You may want to review all of the treatment compared to the patient's stage at diagnosis.

•Recurrence data should be reviewed in registries that have several years of follow-up. Analysis could include disease free intervals, and what types of recurrence patterns were seen. The committee may also want to know if (or how) the recurrence was treated.

•Survival is required in all ACOS-approved registries that are at least five years old. NCDB requires comparison to their survival, which is the observed rate. You may also wish to look at relative rates and compare to other national information available.

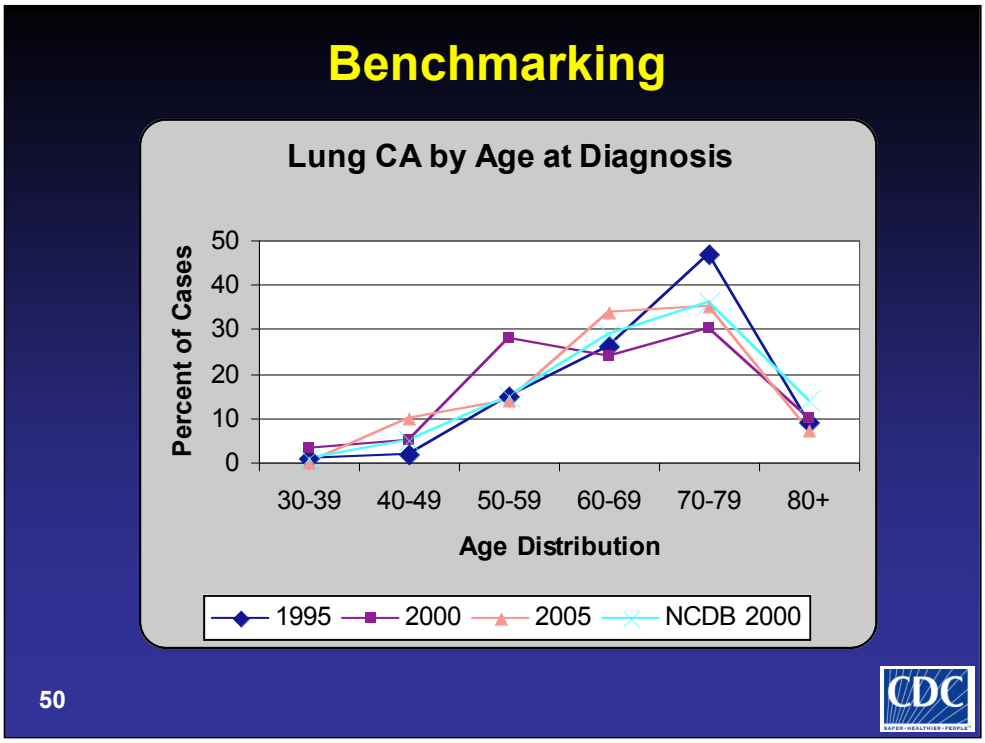


Counting and calculating the percentages may fall on the registrar. What is the percentage of cases in 1995 that were found in the upper lobe (C34.1)? To determine that, take 47 and divide it by 99 (the total number of cases in 1995). You would get 47%. Similarly, in 2005, 60 cases divided by 130 total cases shows 46%.

You would want to calculate these either in two different tables (one with numbers, one with percentages, or combine them into one table for the physician to review.

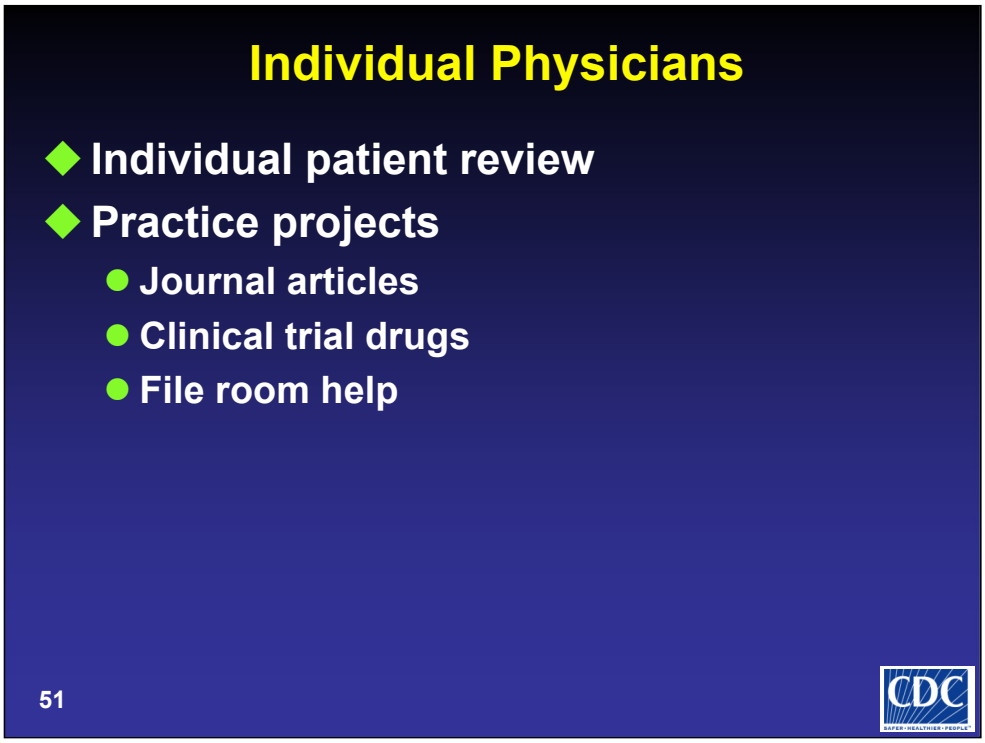
Every variable can be analyzed and displayed this way. The registrar can work with the physician advisor to determine which variables should be graphed to include in the study.

In 2005, there were 40 cases of C34.3. This is a very large increase. Perhaps the registrar should pull those cases and check the site codes? Also, C34.9 shows an increase. Could these be coded more specifically?



We have talked about using tables versus graphs. This data could have been presented in a table. However, by graphing it, we see there may be a slight shift toward diagnosing patients at a younger age when the three different study periods are compared. This may cause the committee to ask whether that trend would continue if you reviewed every year between the study points, which may generate another data request and use of your data!

When possible, go to the websites we have already discussed and compare your data to one of the national standard-setters' data. This gives physicians a point of reference from which to review your data. It may also lead to more questions about the study, more studies about your data, or even a quality or improvement project based on the data. However, that might not happen based on the age at diagnosis. What if you could show a trend that your patients are being diagnosed at later stage than the national data? That might lead to establishing a screening program or more community education about the disease—a vital use of your registry data.

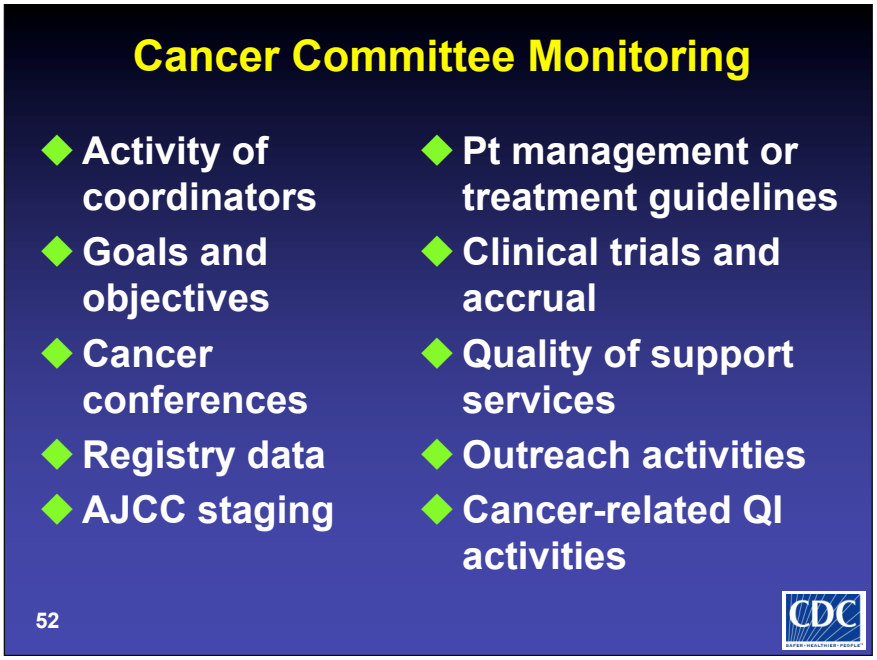


Check with your facility. Most allow a physician to review his individual patient records. A surgeon may request a listing from the registry of all patients who had mastectomy, for example. The registrar should release only the names of those patients on whom that surgeon operated. Be sure to follow your facility's guidelines for data release.

If the physician belongs to a group practice, there may be other opportunities to provide data. One of the physicians in the group may be writing a journal article and ask to see a listing of all of the group's patients. The registrar should review this request with a manager or committee chair (we will discuss this later in the presentation). Because the group is covered as a legal entity, it may be possible to release that information with the permission of all of the partners within the group.

Let's say that the group is interested in participating in a clinical trial for a new drug. The request may come for all breast cancer patients treated by the group who were Her2neu positive, but who had not received Herceptin. If this information is maintained within the registry, it may be possible to develop a list for analysis (after appropriate review).

The registrar is aware when patients die, but frequently doctors' offices may not have that information. If requested, the registrar could provide a list of deceased patients for that practice to the office to enable them to send their files and/or films to storage. This may also be done with hospital departments such as the Radiation Therapy department.



Search for the word “monitor” within the COC Standards and you will find that the Cancer Committee is very busy. Registrars may be helpful in the monitoring of any of these topics, depending on how active or large the committee is.

The coordinators should be reporting at least yearly on their assigned activities.

Goals and objectives should be set and may need review half-way through the year to ensure the committee is still on target.

While there is an activity coordinator for cancer conferences, it may be the registry that is keeping the information about number of cases, attendance, prospective vs retrospective, etc.

There is a whole section within the COC standards on how the registry should be monitored and what could be reviewed. These need to be discussed with the coordinator, especially in terms of time to complete the committee’s data requests.

The registrar may be reporting on the accuracy and frequency of staging, although it is the committee’s responsibility to address problems.

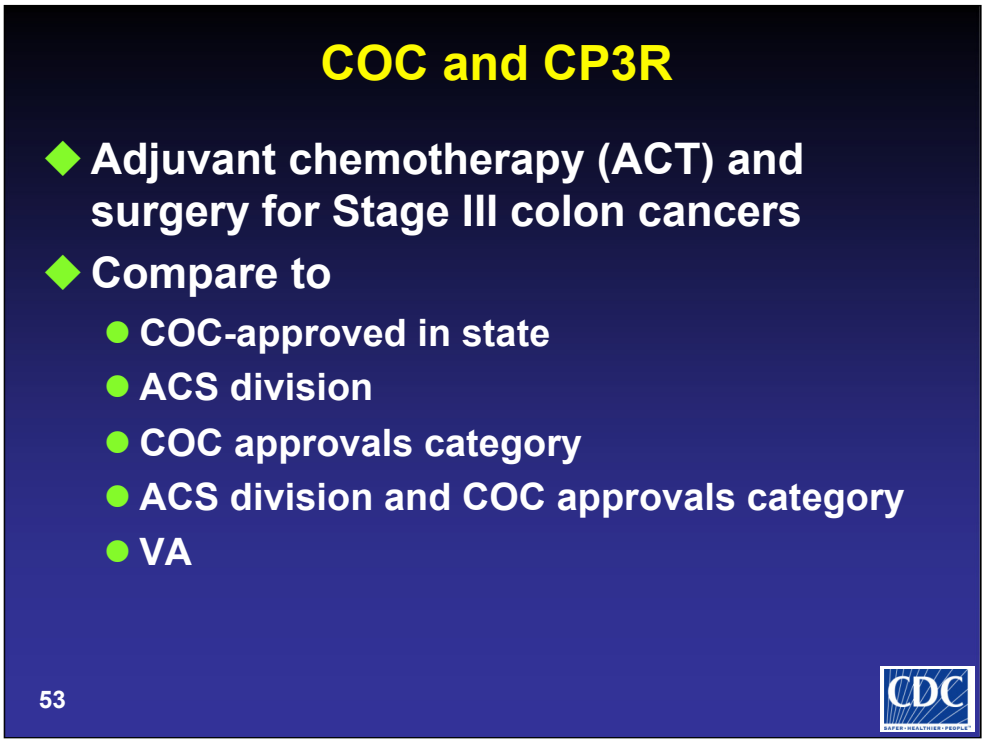
If guidelines (either for management or treatment) are being followed, they should be monitored and reported routinely. Currently, the only guideline in place for most of us is use of the CAP protocols. Your facility may be following NCCN or other guidelines. You should report how many times the guidelines are applied, versus how many exceptions are noted.

If your program is large enough to require a certain percentage of accrual for patients on clinical trials, who is tracking that? It might be a cooperative effort of the clinical trial nurse and the registrar, since we can count those trials done in the physicians’ offices and the trial nurse may be unaware of them.

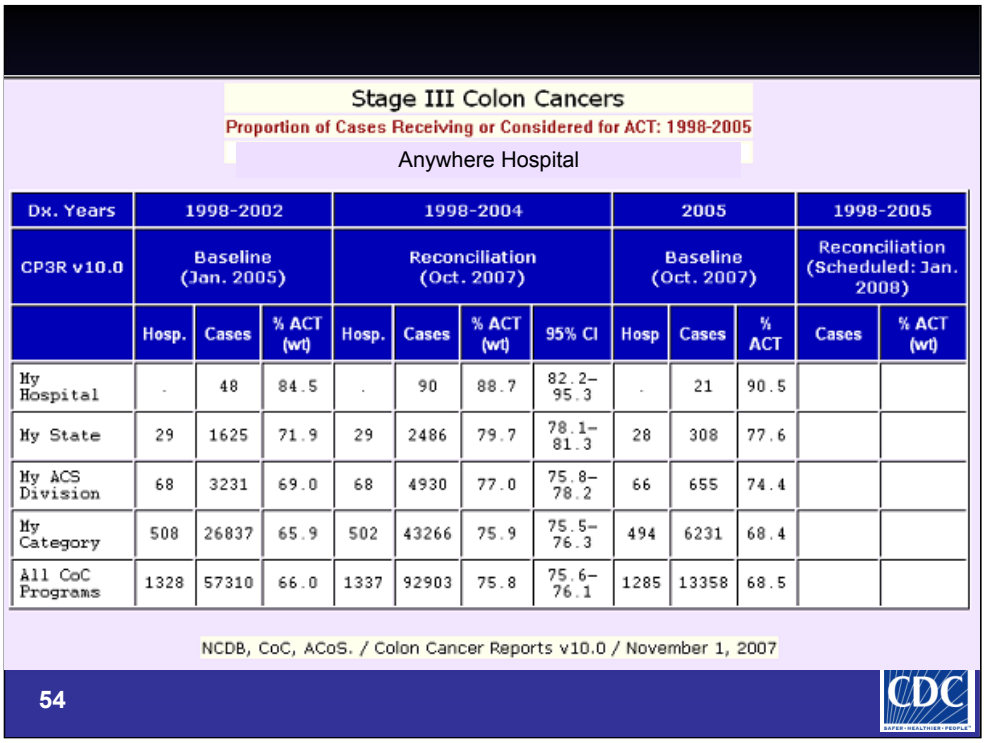
Support services need to be reviewed at least yearly to ensure that the needs of the patients are being met. This may be a review of what is offered as well as how often it is utilized (for example, a quarterly report from the physical therapy department on how many patients are seen for lymphedema.)

At least yearly, the outreach activities (e.g., health fairs, screenings, speakers bureau) should be tabulated and reported.

Any cancer-related quality activities in the facility should also be reviewed by the cancer committee. This may be a simple courtesy review of the work of another committee, but it allows for a better view of the total picture if the committees work together.



The first patient care monitor sent to approved programs by the COC was the CP3R (Cancer Program Practice Profile Reports). This monitor reviewed Stage III (lymph node positive) colon cancer patients, and whether they were offered chemotherapy along with surgery. The data for an individual hospital may be compared to the other categories listed on the slide.



Stage III Colon Cancers

Proportion of Cases Receiving or Considered for ACT: 1998-2005

Anywhere Hospital

Dx. Years	1998-2002			1998-2004				2005			1998-2005	
CP3R v10.0	Baseline (Jan. 2005)			Reconciliation (Oct. 2007)				Baseline (Oct. 2007)			Reconciliation (Scheduled: Jan. 2008)	
	Hosp.	Cases	% ACT (wt)	Hosp.	Cases	% ACT (wt)	95% CI	Hosp	Cases	% ACT	Cases	% ACT (wt)
My Hospital	.	48	84.5	.	90	88.7	82.2–95.3	.	21	90.5		
My State	29	1625	71.9	29	2486	79.7	78.1–81.3	28	308	77.6		
My ACS Division	68	3231	69.0	68	4930	77.0	75.8–78.2	66	655	74.4		
My Category	508	26837	65.9	502	43266	75.9	75.5–76.3	494	6231	68.4		
All CoC Programs	1328	57310	66.0	1337	92903	75.8	75.6–76.1	1285	13358	68.5		

NCDB, CoC, ACoS. / Colon Cancer Reports v10.0 / November 1, 2007

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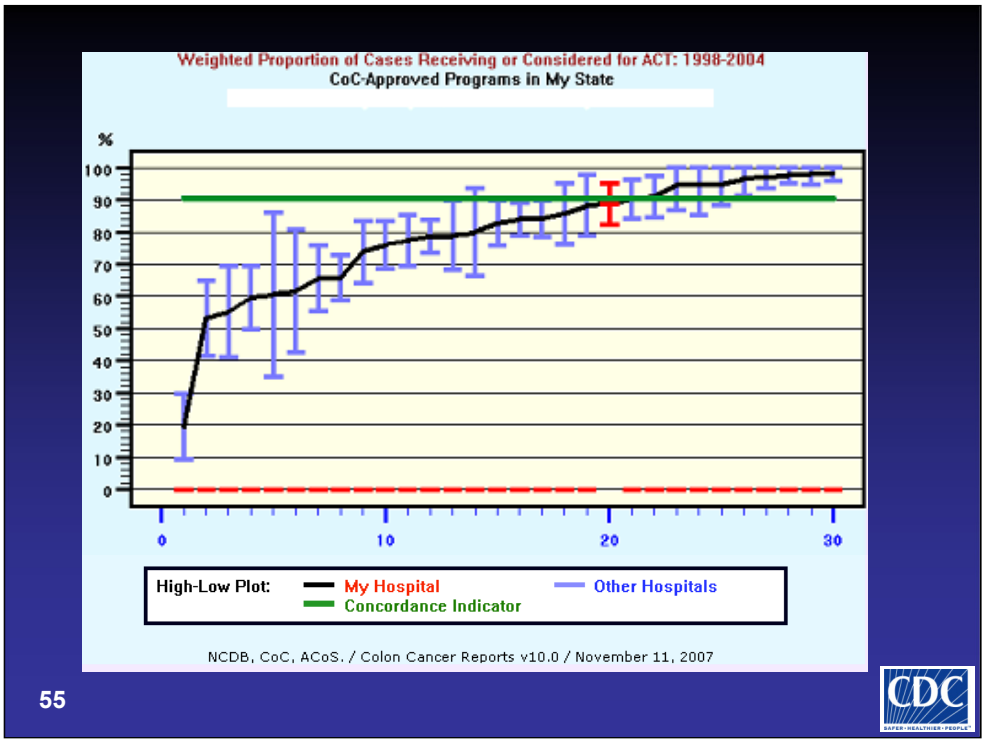
This is a view of the first report generated in the CP3R, the hospital comparison report. This compares Anywhere Hospital to the other categories.

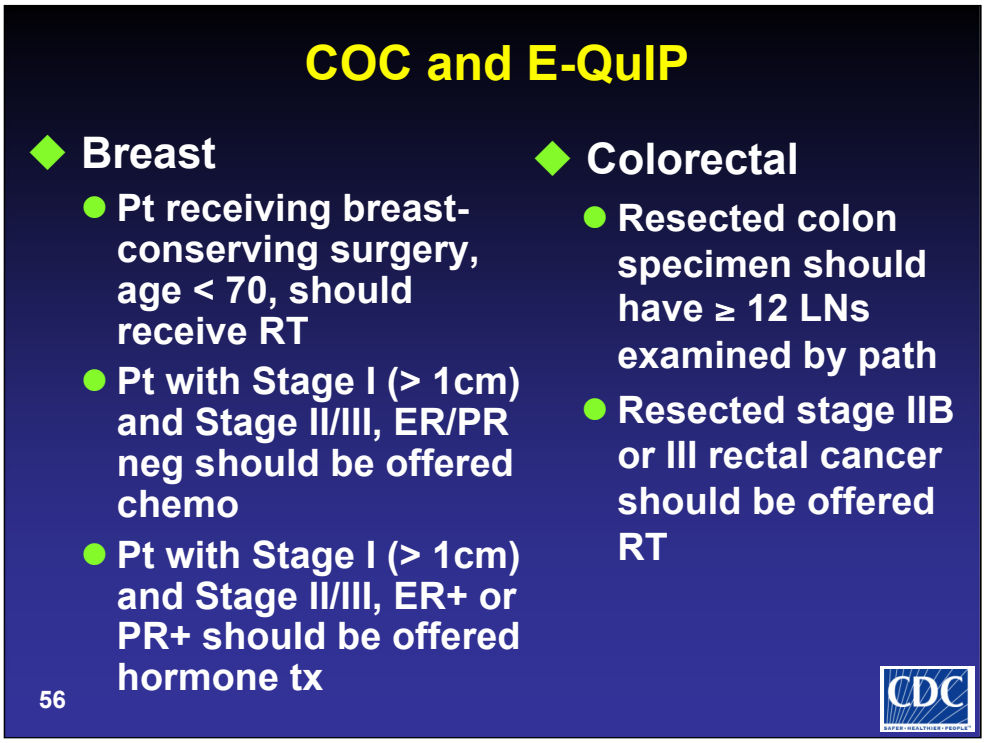
There is a section of the study that allows you to review the individual cases. It is possible something was miscoded, or information was discovered after reporting the case to the NCDB, so the registrar has the opportunity to update the information and alter the statistics. The registrar also has the opportunity to censor the case–that is, remove it from the study because of some factor that does not make it comparable to the rest of the cases. That changes the number of cases in the denominator, and can affect the percentages.

Remind your committee that these are small numbers of cases within each **single** sample year. For example, 1998 only had nine stage III reported cases, and if even one had not been offered chemotherapy, that could greatly affect the percentage. Patients who refuse chemotherapy are calculated as if they were offered it. However the registrar should review the inclusion criteria. For example, patients who had cancer sequence 02 or higher were excluded, as were class of case “0” patients, and patients under age 16. Also, if a patient received chemotherapy plus another drug (such as levamisole, a biologic response modifier which may still have been in use in 1998), the patient was counted as if no chemo was given.

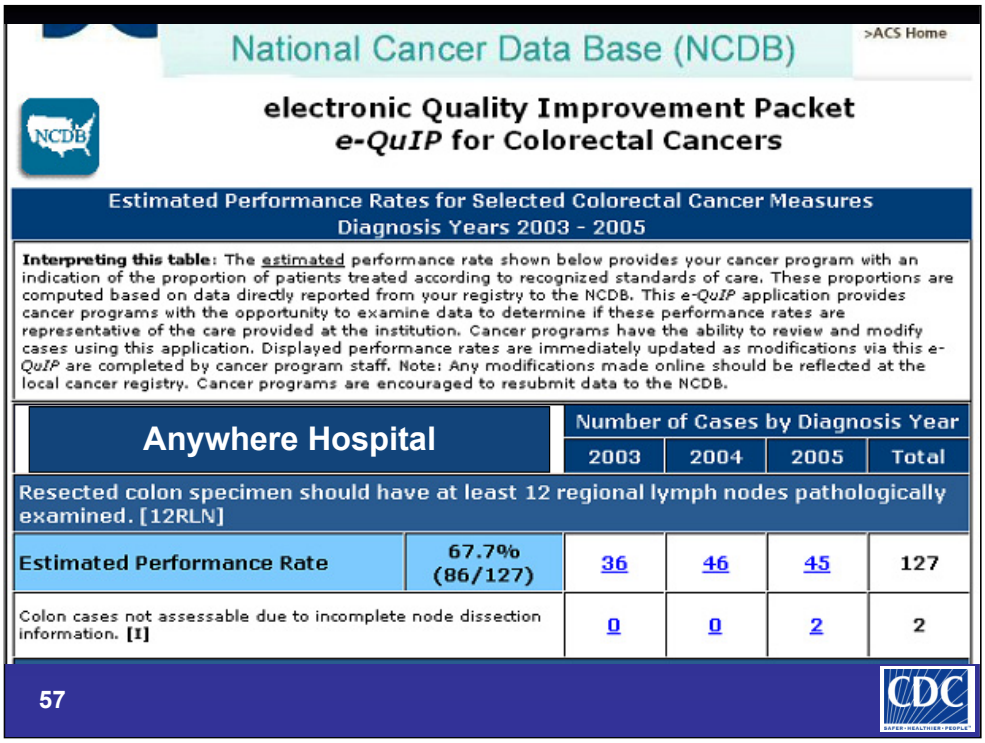


This is another example that can be used by COC approved facilities from the NCDB.

This is the same facility (shown in red on the graph). The **green** line is the Concordance Indicator, and represents those cancer programs ranked in the top 25% of hospitals providing care according to standard of care guidelines. When this study first came out to the registrars, the concordance indicator was at 79%. But as registries have updated their data, the indicator has risen to 90%.



The COC has some newer quality monitors (electronic Quality Improvement Packets, or eQuIP) available in the password-protected section of the NCDB. These are management guidelines from the National Quality Forum, a group that reviews many aspects of medicine and publishes national quality monitors. These measures were approved by the NQF in spring 2007. Registrars in COC-approved facilities should take the information in these monitors to their cancer committee. The NQF looks at a great variety of variables; these are the first cancer sites included and it is unknown whether there will be future indicators developed. Prior to discussion at committee, the registrar should become familiar with the background documentation. For example, in the breast monitor, patients who were male, under age 18, registered on clinical trial, or class of case “0” were excluded from the monitor. Why would this be important? If the committee decides to use these monitors to review other years for the same site, you would want to include only the same type of patients.



National Cancer Data Base (NCDB)

>ACS Home

electronic Quality Improvement Packet
***e-QuIP* for Colorectal Cancers**

Estimated Performance Rates for Selected Colorectal Cancer Measures
Diagnosis Years 2003 - 2005

Interpreting this table: The estimated performance rate shown below provides your cancer program with an indication of the proportion of patients treated according to recognized standards of care. These proportions are computed based on data directly reported from your registry to the NCDB. This *e-QuIP* application provides cancer programs with the opportunity to examine data to determine if these performance rates are representative of the care provided at the institution. Cancer programs have the ability to review and modify cases using this application. Displayed performance rates are immediately updated as modifications via this *e-QuIP* are completed by cancer program staff. Note: Any modifications made online should be reflected at the local cancer registry. Cancer programs are encouraged to resubmit data to the NCDB.

Anywhere Hospital		Number of Cases by Diagnosis Year			
		2003	2004	2005	Total
Resected colon specimen should have at least 12 regional lymph nodes pathologically examined. [12RLN]					
Estimated Performance Rate	67.7% (86/127)	36	46	45	127
Colon cases not assessable due to incomplete node dissection information. [I]		0	0	2	2

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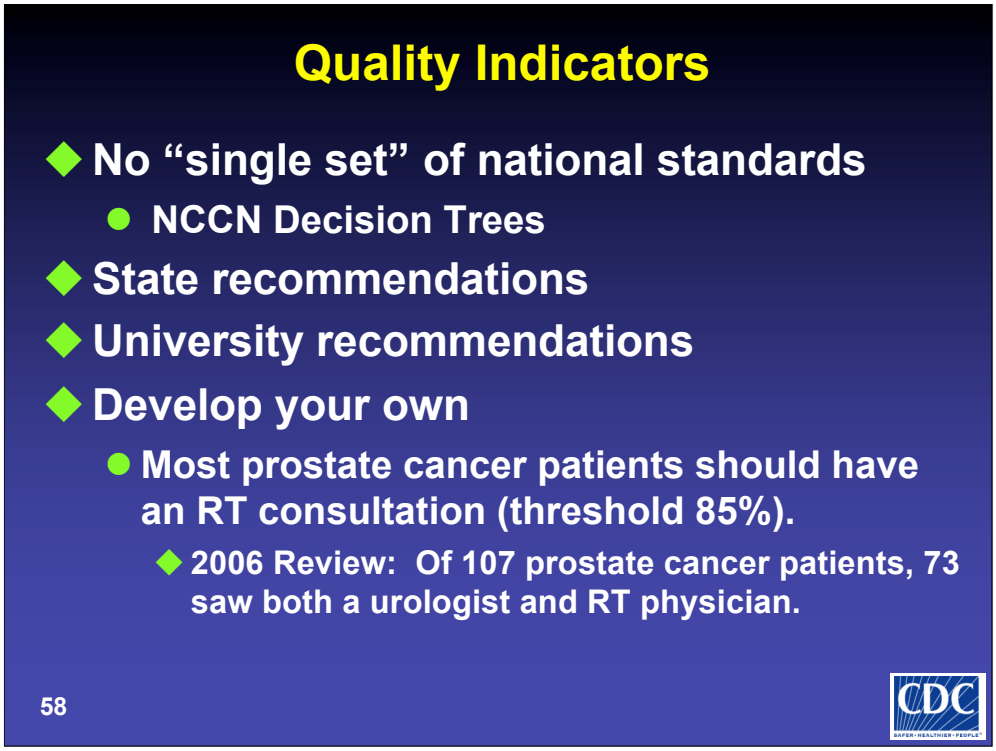
This is what one of the monitors looks like. The estimated performance rate for this facility is only 67.7%. That doesn't sound very good. But look at the years being monitored. The quality measure "number of lymph nodes" was not approved until spring 2007. It may not be fair to apply a current guideline to older data. However, reviewing the older data can give a good base to show improvement. This registry should continue to monitor the data for the next few years to see if there is improvement up to a more acceptable percentage.



A search of a multitude of Web sites for other quality indicators of cancer care showed that there is no single set of indicators available for any particular cancer topic.

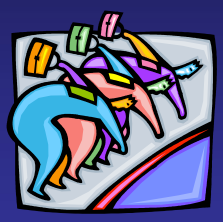
National Comprehensive Cancer Network (NCCN) and ACS have collaborated on Treatment Guidelines for many cancer sites. Your committee may be able to review these and choose variables about workup and/or treatment to include as facility indicators. There may be some states in which the medical societies have developed indicators for voluntary use within facilities. The same could be said of universities or consortia treating patients.

If the cancer committee wishes to develop their own indicators, the registrar often assists in this process and should keep in mind that the simpler you can keep the criteria, the more useful it might be. The committee should set a threshold of what is acceptable. The committee also needs to determine the policy of how to deal with cases that are at variance from the criteria. If the committee is not empowered to conduct peer review, what is the mechanism for reporting variances?

In the example on the slide, the criteria are fairly straightforward. There should be documentation (either a consultation conducted within the facility, or mention of it in the urologist's dictated notes) of a consultation with a radiation therapist. In the review of the cases from 2006, the threshold was not met (fewer than 85% of patients accomplished it). In reviewing the 34 patients who did not meet the criteria, it was noted that 14 patients had documentation that they were offered the consultation and refused. Is that an acceptable variance? That is up to your cancer committee to decide. Of the 20 patients remaining, eight were over age 80, and chose Watchful Waiting as their first course of therapy. Is that an acceptable variance? Note that the review was not reported by individual physician. While the QI person may have noted a pattern, this committee was not approved for peer review. If the cancer committee wants to recommend further action, they might send this study onto the peer review committee for surgery where the practices of the individual physicians can be reviewed for patterns and/or action.

Other Measurements

- Clinical Pathways
  - aka critical pathway, care path
  - Reduce cost, resource utilization
- Practice Parameters
  - Review of literature
- Outcomes Measures
  - Results of actions taken



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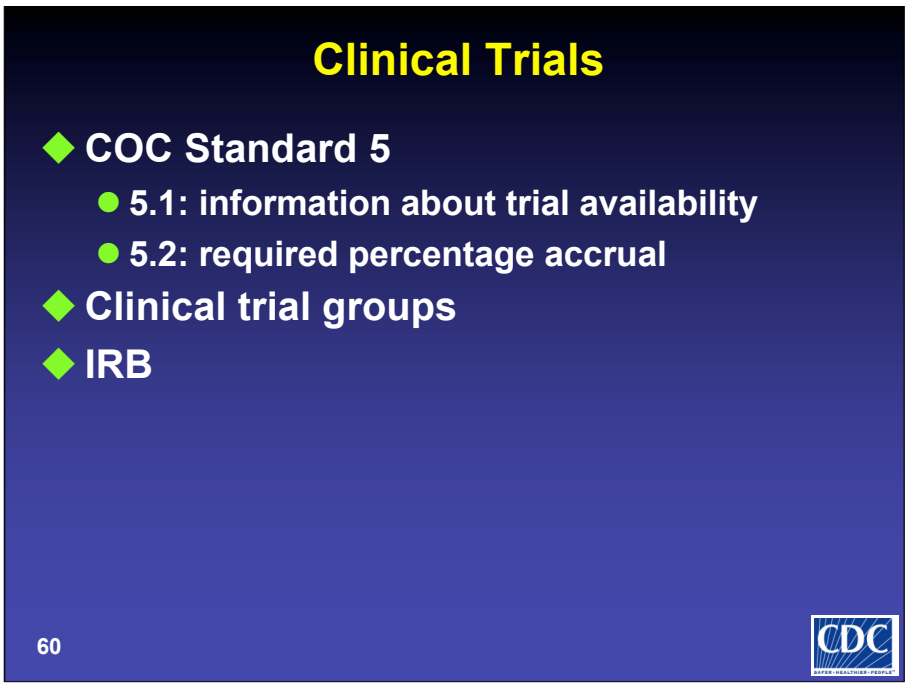
A clinical pathway is more involved than a quality indicator. It is a series of steps in the diagnosis and treatment of individual patients with similar diseases. It's a management plan to ensure efficiency as well as consistency.

According to an article in the *Annals of Surgical Oncology* (vol 7, 2000), clinical pathways may be effective in reducing cost and resource utilization in common procedures, although they may not be as useful in complex surgeries.

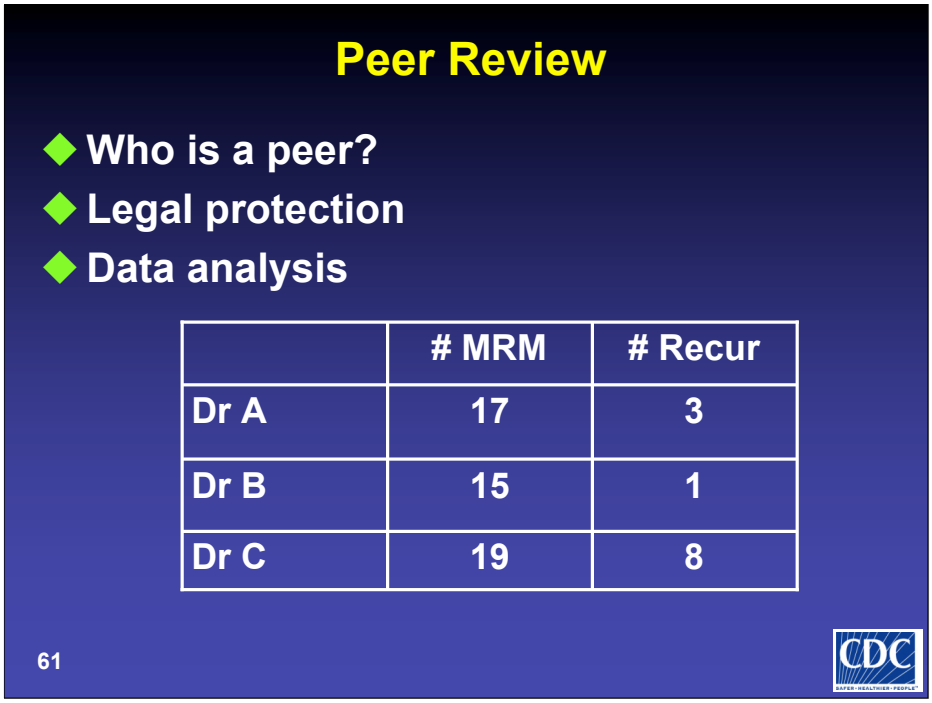
Practice parameters are strategies for patient management that assist physicians in clinical decision making. A practice parameter is one or more specific recommendations based on analysis of evidence on a specific clinical problem (*Neurology* 2000, Vol 54). For example, should newly diagnosed brain tumor patients be given prophylactic anticonvulsants? The *Neurology* article documented the review of 12 different articles, including four of those with level I evidence. The recommendation after this meta-analysis was new patients should not be given prophylactic anticonvulsants as there was no evidence that it provided benefit when compared to the side effects generated.

The definition of "Outcomes Measures" is "the tabulation, calculation, or recording of activity or effort that can be expressed in a quantitative or qualitative manner," according to the Center to Advance Palliative Care. For some of the outcome measures you may have seen in the past– patient satisfaction, quality of life, or disease-free survival–an action was done for the patient and the outcome could be measured either in quantitative results (number of disease free months) or qualitative results (patient could continue to play golf).



What is a clinical trial? “A clinical trial is a research study designed to test the safety and/or effectiveness of drugs, devices, treatments, or preventive measures in humans” (definition from Rush University Medical Center). The COC considers the availability of clinical research to be an important part of a well-rounded cancer program. At a minimum, COC-approved facilities must offer patients information about clinical trials and their availability. This can be through brochures, articles, access to the internet or other resources. The cancer committee should be aware of how the information is presented and what is available. If the cancer program is larger, there may be a requirement that a certain percentage of analytic cases must be entered into a clinical trial on a yearly basis. The percentage varies from 2% for Community Hospital Comprehensive Cancer Programs to 10% for NCI-designated facilities. Most community hospitals are not set up to conduct individual research. They are allowed to participate in Clinical Oncology Program groups such as POG (Pediatric Oncology Group) or SWOG (Southwest Oncology Group), and so forth, where the clinical trials are developed by researchers approved by the National Cancer Institute or another peer-review research body. The COP approves the use of specific trials for its member organizations and assists in conducting the specifics of the trials, such as when does a patient need a chest X-ray, how often does blood need to be taken, etc.

Any research on human subjects must be approved by an internal or external Institutional Review Board. The cancer registrar at the facility may be involved in documenting the number of patients on a clinical trial up through actually sitting as a member of the IRB. Be aware of their rules. A physician wanting to review old cases may need to get the permission of the patient if he/she is no longer caring for the patient in order to conduct a study.



We've discussed this several times, but what is peer review? The following is a good definition even though it comes from a software development Web site, http://searchsoftwarequality.techtarget.com/sDefinition/0..sid92_gci936459,00.html. "Peer review is a process used for checking the work performed by one's equals (peers) to ensure it meets specific criteria. Peer review is used in working groups for many professional occupations because it is thought that peers can identify each other's errors quickly and easily, speeding up the time that it takes for mistakes to be identified and corrected."

In our discussions, peer review usually refers to physicians evaluating the practices of other physicians. The assumption is made that as physicians, they have all had similar training and would understand the mechanisms of patient care. True peer review is protected under the law as providing a fair and unbiased review of someone else's work. There are many levels a peer review may go through when discussing a potential error of a physician; steps including review by a peer, decision to take the issue to the committee, action taken by the committee including inquiry or censure, further recommendations to other peer review committees, even up to an Executive Committee level for action. Most cancer committees are not defined by their facility bylaws as peer review committees. If the registrar is unsure how to proceed, speaking with the chair or manager of a peer review committee can provide guidance. One reason we are including this here is that there are legal ramifications, from monetary fines to being sued to dismissal, for violating the steps involved.

Peer review is not always punitive. A simple example of peer review for registries is the *Journal of Registry Management*. Articles in there are peer reviewed. At least 3 other reviewers who hold similar degrees and/or occupations review the article prior to its publication. This gives the peers an opportunity to ask questions about the article or even catch minor errors.

What if we had been trying to show three individual doctors and how often their patients had mastectomy in one column and the frequency of recurrence in another column? It would appear that Dr C has a high recurrence rate compared to the other two. What other factors could play a part in the recurrence rate? What if Dr C had more Stage 3 patients? What if one or two patients refused chemo? The interpretations of the data would be better left to physicians who will review the entire record and determine whether outside influences such as comorbidities, patient refusal for chemotherapy, etc., led to altered outcomes.

Physician Practice Profiles

- Facility
- Insurance companies
- Internet groups

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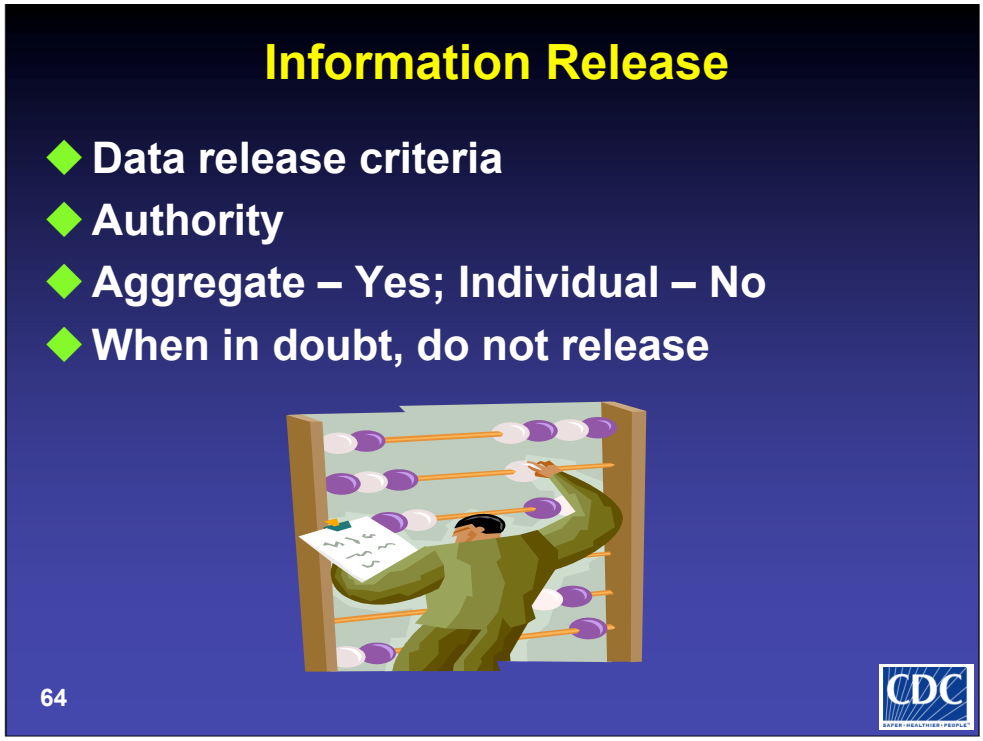
Physicians and how they practice may be profiled. What does that include? A listing on the facility Web site that may include the physician's degrees and honors earned, as well as the types of insurance the physician will accept. Insurance companies may conduct patient satisfaction surveys and evaluate the physicians within their groups. Or they may evaluate the physician compared to DRG groups or a severity-of-illness index they design. They may monitor outcomes.

There are also groups who have Web sites dedicated to allowing patients to review a physician. One of these is RateMDs.com.

The registry may be asked by the facility to contribute numbers of cancer patients seen by individual physicians or procedures done. Any request of this type must be approved by a supervisor, peer review committee, or institutional review board.

Community Usage



All registries should include data release criteria and the authority required to release that data within their policies and procedures. The cancer committee should be involved in the decisions about any data release that involves the registry. They may decide on a blanket policy that allows the registry to release aggregate data about diseases, stage, and treatment to certain sources. They may recommend that the registrar seek permission of her/his manager. The cancer committee chair might need to approve requests for data if the registrar is new or uncomfortable with what is being sought.

Does the requestor have the authority to make this request? Administration may see any medical record necessary to conduct business, so they may have a blanket authority. On the other hand, the nurse manager on the oncology unit may not have the authority to request a list of breast cancer patients because some were treated in the radiation oncology department or another facility. The registrar should never discuss data with a newspaper reporter. Company policy usually supersedes the cancer committee, and usually requires the registrar to refer the reporter to the public relations department or another designated department.

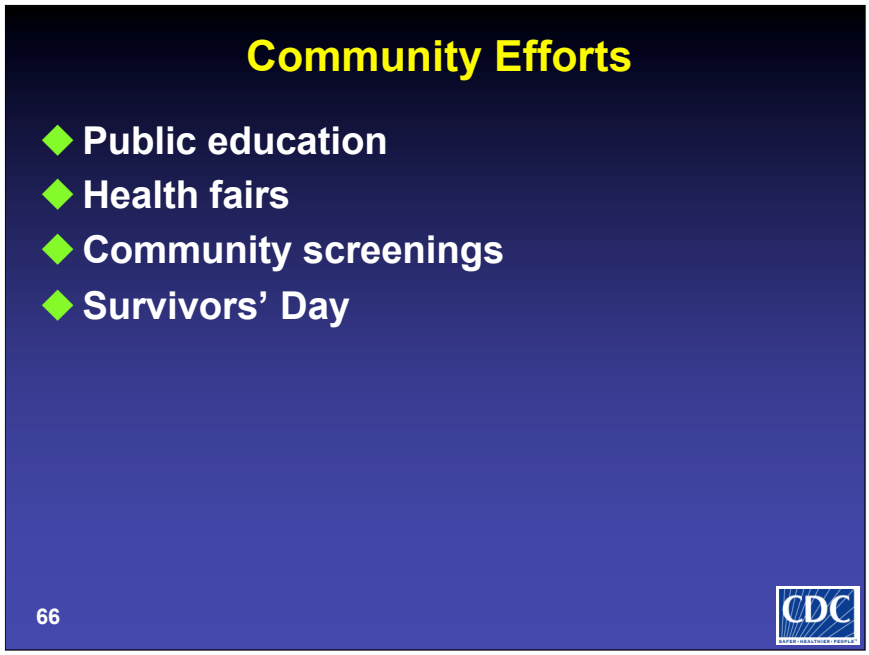
Usually the registrar may feel comfortable releasing aggregate data to most requestors with committee approval. Data identifying individual patients or individual physicians should be discussed with someone of more authority.

When releasing data, be careful to exclude data when there are too few cases within the sample. For example, the American Cancer Society asks for a count of how many patients are seen by county at your facility. If there are less than 10 patients within one or more counties, it might be safer to censor those (that is, remove them from the study) in order to offer protection against potential identification. The registrar may place an asterisk or other symbol to show that some patients were documented but an exact number is not available.

When in doubt, do not release any data without seeking guidance.

There may be groups outside the facility who need the data included in the registry. Hospices may request numbers of cases. he local Leukemia Society may be interested in what types of leukemia are seen at your facility. Your facility may not have a regular support group, but if there is one in a close town that meets for breast cancer survivors, they might request treatment and survival information. Drug vendors may request the number of cases of cancer in order to decide whether they should approach physicians in your facility. And we've already discussed the media, who may ask a multitude of things but need to be referred to someone who has the authority to speak with them.

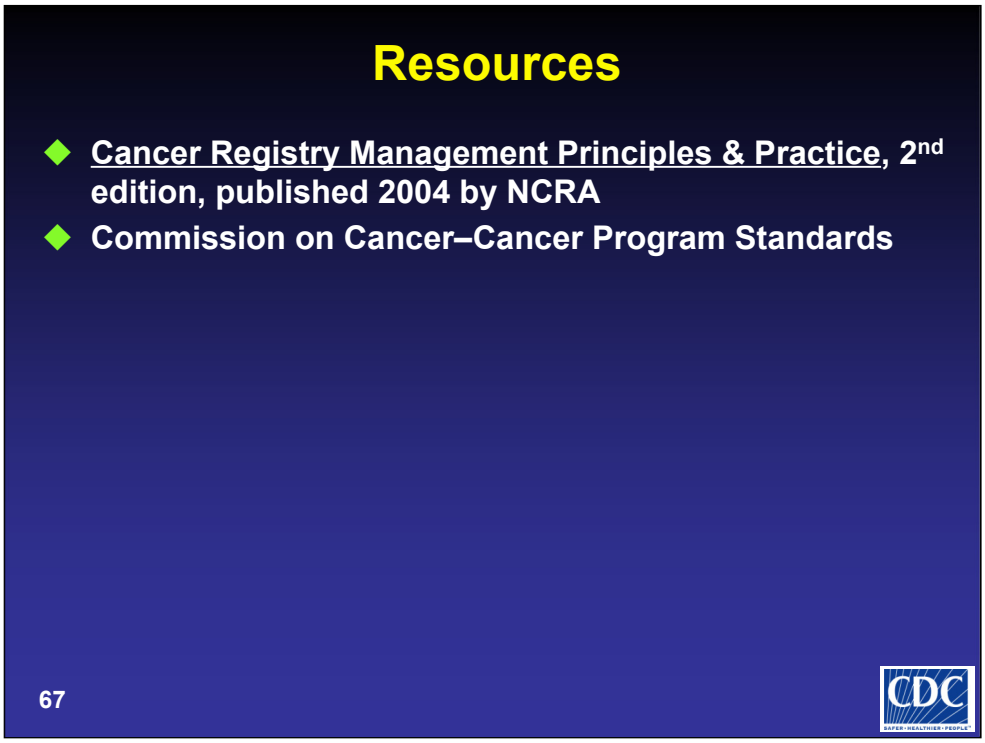
Any information that is not available in an annual report should be released only with the approval of a supervisor or the cancer committee. A registrar should never release information about a specific patient, except under the guidelines of your facility or state law. (For example, you may share information about patient treatment with another registrar who has the same patient and needs to complete her report of the radiation done at your facility.)



The opportunities listed on this slide to share data may be more intimately involved with the cancer committee or departments within the facility. If your public relations department routinely sends a newsletter out for publication, try to get some cancer information including registry data in every issue. Participate in health fairs both by submitting data and by joining in with your co-workers. Community screenings may be conducted along with a health fair, or done at a special time. Either way, it's an opportunity to develop registry data for the specific site being screened.

Survivor's Day can present a HIPAA dilemma. While you would like to notify any survivors, you must take care not to violate their privacy by identifying them as a survivor.If it's only a postcard being sent, a specific list of patients is not appropriate. That patient's name can be read by anyone, including the mail carrier, and the presumption is the mail recipient has a cancer diagnosis. With postcards, it would be better to market to whole neighborhoods and include "OCCUPANT" or "OUR FRIEND AT" in the addresses of all. This is more protective of privacy. And it is better marketing. Just because the person receiving the card didn't get treatment at your facility does not mean he or she is not a survivor. Why not include the whole community in the celebrating? If the information is going out in a closed envelope, the registry could help with names and addresses depending on the policy of the facility. The hospital does not want to send a notice to a patient who has died. The registry can help there.

It is possible that an IRB within your facility will need to approve this use of your data or you may need approval from the legal department.



Other registrars may be the best resources to discuss data usage and interesting ways to display the data. Share with each other!

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

For information about CDC's
Cancer Prevention and Control Programs
and the
National Program of Cancer Registries

Please visit

www.cdc.gov/cancer/npcr